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Proponents of prostate cancer early detection argue that the combination of digital rectal examination and prostate-specific antigen testing is effective and that early detection leads to improved chances for survival. Others caution against routine screening because no mortality benefit has been shown in randomized trials and treatment of diagnosed prostate cancer can have serious side effects. Typically, patients who undergo testing are not aware of these uncertainties and do not participate in deciding whether to screen. We are conducting a prospective study with men 50-69 years of age to evaluate the efficacy of a counseling intervention designed to promote value-based decision-making. A baseline survey questionnaire will be administered to measure demographic, cognitive, and psychosocial characteristics. A Standard Intervention Group will receive a generic educational booklet about prostate cancer early detection. Enhanced Intervention Group men will receive a theory-based educational counseling session the booklet will be enhanced by an Analytic Hierarchy Process educational counseling session delivered by a health educator. The session will engage participants in a personally-tailored process of evaluating whether to have or not have an early detection exam. The behavioral outcome will be the proportion of men in each group who have an early detection exam during a six month follow up period. This outcome will be measured using data obtained via medical chart audit. Cognitive and psychosocial outcomes will be assessed using endpoint survey data.

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## Introduction

Proponents of prostate cancer early detection argue that the combination of digital rectal examination and prostate-specific antigen testing is effective and that early detection leads to improved chances for survival. Others caution against routine screening because no mortality benefit has been shown in randomized trials and treatment of diagnosed prostate cancer can have serious side effects. Typically, patients who undergo testing are not aware of these uncertainties and do not participate in deciding whether to screen. We are conducting a prospective study with men 50-69 years of age to evaluate the efficacy of a counseling intervention designed to promote value-based decision-making. A baseline survey questionnaire was administered to measure demographic, cognitive, and psychosocial characteristics. A Standard Intervention Group received a generic educational booklet about prostate cancer early detection. An Enhanced Intervention Group received a theory-based educational counseling session. The booklet was enhanced by an Analytic Hierarchy Process educational counseling session delivered by a health educator. The session engaged participants in a personally-tailored process of evaluating whether to have or not have an early detection exam. The behavioral outcome is the proportion of men in each group who have an early detection exam during a six-month follow up period. This outcome was measured using data obtained via medical chart audit. Cognitive and psychosocial outcomes will be assessed using endpoint survey data.

Specific aims of this Phase I study are to:

- (1) Develop and pilot test an intervention (i.e., an educational booklet and educational counseling) intended to facilitate informed decision making about prostate cancer screening;
- (2) Measure intervention impact on screening; and
- (3) Evaluate intervention effect on patient knowledge, attitudes, and beliefs.

We hypothesize that exposure to educational counseling will affect prostate cancer screening and related perceptions.

## Body

### Baseline Survey

A total of 199 Baseline Surveys were completed with Jefferson Internal Medicine Associates (JIMA) patients. Of this total, 103 (52%) were completed via telephone by the survey sub-contractor. An additional 96 (48%) men completed and returned a printed, self-administered version of the survey that was mailed to them.

Table 1 shows descriptive characteristics of men who completed the Baseline Survey.

Table 1 — Baseline Survey Responder Characteristics			
Variable	Response category	Number	Percent
Age	50 to 59 years	140	70.4
	60 to 69 years	59	29.6
Place of birth	Philadelphia	90	45.5
	Other US location	99	50.0
	Foreign	9	4.5
Race / ethnicity	White	147	74.6
	Black	41	20.8
	Other	9	4.6
Education	< 12 years	14	7.0
	12 years	46	23.1
	> 12 years	139	69.9
Marital status	Not married	54	27.3
	Married	144	72.7
Family history of prostate cancer	No	181	91.0
	Yes	18	9.0
DRE and PSA in previous 12 months	No	112	56.3
	Yes	87	43.7

Cognitive and psychological representations, social support and influence, and intention related to prostate cancer screening were also measured on the Baseline Survey. These additional data are not reported here, but will be included in planned analyses of study outcomes.

## **Assignment of Survey Responders to Study Groups**

According to the research design, men who completed the Baseline Survey were randomly assigned to one of two study groups: Standard Intervention Group (N=99) and Enhanced Intervention Group (N=100). Within the study groups, men were also randomly assigned to one of five cohorts. Each cohort was targeted, in turn, to receive study contacts.

## **Contacts with Men in the Study Groups**

Men in the Standard Intervention Group received a generic educational booklet about prostate cancer early detection. Enhanced Intervention Group men also received the booklet. In addition, they were invited to participate in an educational counseling session delivered by a health educator. Overall, 60 men (60%) went through the educational counseling session. The remaining 40 (40%) did not go through this session. Reasons for not completing the educational counseling session include: no longer fulfilled original eligibility criteria (N=20), unavailable for contact (N=11), and refused (N=9).

## **Screening Decision Factors Reported by Men in the Enhanced Intervention Group**

Men who participated in the educational counseling session were asked to report spontaneously on their own reasons for wanting to and not to have a prostate cancer screening examination. Preliminary inspection of these responses showed that men DID want to have a screening exam for the following reasons:

- It might show that I have prostate cancer or another serious health problem.
- It might have a positive effect on my health and well-being.
- It is encouraged by my health care provider.
- It is encouraged by my family members and/or friends.

The men also indicated that they DID NOT want to have a screening exam for the following reasons:

- It might show that I have prostate cancer or another serious health problem.
- It might have a negative effect on my health and well-being.
- It is NOT encouraged by my health care provider.
- It is NOT encouraged by my family members and/or friends.
- It is uncomfortable.
- It is embarrassing.
- It is inconvenient.
- It is expensive.

Content analyses are currently underway to produce a final set of categories for decision factors (i.e., reasons that men want to and did not want to have a screening exam).

## **Endpoint Chart Audit**

Endpoint Chart Audits have been completed for all 199 men in the study. The chart audits of the study participants' medical records collected information on whether or not a prostate cancer screening examination was performed. An analysis is currently underway to determine the impact of study intervention on screening behavior.

## **Preparation for Administration of Endpoint Survey**

We plan to administer an Endpoint Survey to study participants. Participants will be mailed the survey questionnaire. The questionnaire will be accompanied by a cover letter from their JIMA physician explaining the purpose of the survey and encouraging completion and return. A postage-paid return envelope will also be enclosed. Prior to survey mailing, a telephone call will be made to all men, verifying current address and telephone number, and notifying them that they will be receiving the survey. If the survey is not returned in 15 days, a reminder telephone call will be made to encourage response.

## **Key Research Accomplishments**

- Completion of baseline survey
- Completion of cohort randomization
- Completion of intervention delivery
- Completion of endpoint chart audit

## **Reportable Outcomes**

### **Publications**

Myers RE. African American men, prostate cancer early detection examination use, and informed decision-making.. Seminars in Oncology 26:375-381, 1999.

Myers RE and Kunkel EJS. Preparatory education for informed decision-making in prostate cancer early detection and treatment. Seminars in Urologic Oncology 18(3):172-177, 2000.

Kunkel EJS, Bakker JR, Myers RE, Oyesanmi OA, and Gomella LG. Biopsychosocial aspects of prostate cancer. Psychosomatics 41:85-94, 2000.

Kunkel EJS, Myers RE, Lartey PL, and Oyesaami OA. Communicating effectively with the patient and family about treatment options for prostate cancer. Seminars in Urology 18:233-240, 2000.

### **Presentations**

Liberatore MJ, Nydick RL, Myers RE, Kunkel EJS, O'Connor J, Christian E, Burgh D, Wolf T, Ohene-Frempong J. A decision support system for men considering prostate cancer early detection. Institute for Operations Research and the Management Sciences, Philadelphia, PA, 1999.

### **Funding applied for based on work supported by this award**

Myers RE, Jennings-Dozier K, Hirsch I, and Kunkel EJS. Informed choice among African American men in the negative biopsy trial: an ACES project pilot study. Submitted to National Cancer Institute Special Populations Network, 2001.

## **Conclusions**

In accordance with the original study design, we assigned a total of 199 men either to a Standard Intervention Group (N=99) or an Enhanced Intervention Group (N=100). Although we invited all men in the Enhanced Intervention Group to participate in an educational counseling session, only 60 (60%) actually completed the educational counseling session. Of the 40 men who did not go through the session, 20 were found to no longer satisfy initial study eligibility criteria, 11 could not be located, and 9 refused to participate. Future efforts will need to focus attention on increasing the proportion of eligible men who participate in the educational counseling session.

For men who participated in the educational counseling session, each was able to report one or more reasons why he would or would not want to have a prostate cancer screening examination (decision factors), weight the decision factors in terms of their importance, and compare the decision factors in pairwise fashion. This experience highlights the fact that it is feasible to elicit decision factors from men who are considering prostate cancer screening. Using these data, we will be able to generate a numeric decision score that indicates the individual's decision (i.e., to have an exam, no preference, or not to have an exam) and correlate this score with actual screening behavior.

We have succeeded in completing an Endpoint Chart Audit for each study participant who was randomized to one of the study groups. Data on screening behavior has been obtained from the chart audit. These data are currently being tabulated and will be provided in the final report.

In the coming months, each study participant will be mailed an Endpoint Survey questionnaire. This instrument that will be administered to Standard Intervention Group men includes items from the Baseline Survey. The Endpoint Survey for Enhanced Intervention Group men also includes these items, along with process measures related to exposure to the intervention.

Final data analyses will draw on data collected through the Baseline Survey, the educational counseling session, the Endpoint Chart Audit, and the Endpoint Survey. These analyses will allow us to report on measures of screening-related knowledge, attitudes and beliefs; characterize factors involved in decision-making related to prostate cancer screening; and identify predictors of screening behavior, including exposure to educational counseling.

## **References**

Not applicable.



## **Appendices**

### **Journal Articles**

- Preparatory education for informed decision-making in prostate cancer early detection and treatment.
- Biopsychosocial aspects of prostate cancer.
- African American men, prostate cancer early detection examination use, and informed decision-making
- Communicating effectively with the patient and family about treatment options for prostate cancer.

### **Study Questionnaires and Surveys**

- Endpoint Chart Audit
- Endpoint Survey

### **Abstract from funding applied for based on work supported by this award**

- Informed choice among African American men in the negative biopsy trial: an ACES project pilot study.

# Preparatory Education for Informed Decision-Making in Prostate Cancer Early Detection and Treatment

Ronald E. Myers, PhD, and Elisabeth J. S. Kunkel, MD

**Patients are expected to assume increased responsibility for self-management in health care. However, little attention has been directed to the problem of preparing individuals to play a more active role in the physician-patient relationship. Preparatory education about prostate cancer early detection and treatment is needed to enable patients to recognize the importance of their role in medical decision-making, voice personal values and preferences related to health care choices, and make informed choices under conditions of uncertainty about possible outcomes. Effective decision aids are needed to facilitate shared decision-making in the context of the physician-patient relationship along the continuum of prostate cancer care. Decision aids for patients have taken the form of informational booklets, scripted telephone counseling, decision boards, educational videotapes, interactive videodiscs, computer programs, and Internet Web sites. The impact of preparatory education and the use of decision aids should be evaluated in terms of change in knowledge and understanding, shifts in decision preferences, health care utilization, and satisfaction with care. The need for this type of patient interaction will grow as technology increases patient access to health care information.**

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**Key words: Prostate cancer, screening, treatment, decision aids, and shared decision-making.**

The American Urological Association<sup>1</sup> and the American Cancer Society<sup>2</sup> recommend that men who are 50 or more years of age and have a life expectancy of 10 or more years should be offered a digital rectal examination (DRE) and a prostate-specific antigen (PSA) test on an annual basis and that screening should be considered at an earlier age for men under 50 years who are at high risk (ie, African

American men and men with a family history of prostate cancer). Guidelines put forward by the United States Preventive Services Taskforce and the Canadian Taskforce on the Periodic Health Examination do not support routine prostate cancer screening.<sup>3,4</sup> The American College of Physicians has also recommended against prostate cancer screening among older adult men and has suggested that if screening is performed, men should be advised in advance about the potential benefits and harms of prostate cancer early detection.<sup>5</sup> This lack of consistency in recommendations reflects the fact that there are different interpretations of the available scientific evidence on prostate cancer early detection.

Health care professionals who support routine prostate cancer screening point out that combined DRE and PSA testing is effective at identifying men with early prostate cancer. In addition, they cite evidence that men who are diagnosed with localized prostate cancer and are treated aggressively have higher survival rates compared with men who are diagnosed with late-stage disease.<sup>6,7</sup> Opponents of prostate cancer screening argue that no randomized trials have demonstrated a reduction in mortality as a result of prostate cancer screening.<sup>8,9</sup> In addition, they assert that it is not yet possible to reliably differentiate indolent from aggressive prostate cancer, and that treatment of early-stage prostate cancer with radical prostatectomy or radiation therapy can cause substantial adverse outcomes (eg, impotence, incontinence, stricture, bowel injury, and even death).<sup>10,11</sup> The arguments outlined herein give many men pause as they consider whether or not to have a screening DRE and PSA test. Unfortunately, results of current randomized trials that are designed to determine whether detecting and treating early prostate cancer has an impact on mortality will not be available for several years.<sup>12-14</sup>

Men who have been diagnosed with tumors confined to the prostatic capsule are concerned about reports that show incontinence and sexual performance to be significant problems for men treated with either radiotherapy or radical prostatectomy.<sup>15</sup>

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A case in point is the results of a recent population-based longitudinal cohort study of patients with localized prostate cancer. The study showed that at 10 months after radical prostatectomy, 8% of the men were incontinent and 60% were impotent.<sup>16</sup> Although prostate cancer treatment techniques have improved substantially and new options will emerge in the future, the elimination of negative side effects from therapy will remain an elusive goal.

It has been well documented that older adult men are not well informed about the nature of prostate cancer, the early detection and treatment alternatives available, and controversies related to prostate cancer early detection outlined above.<sup>17</sup> In addition, it is likely most men are simply not fully cognizant of the fact that choosing to have an early detection examination may require further decisions about undergoing diagnostic evaluation and treatment. There is an acute need for effective preparatory educational materials and methods that can be used to help patients make meaningful health care choices about prostate cancer early detection. Preparatory education materials and methods are also needed to facilitate informed decision-making further along the continuum of care.

### **Preparatory Education for Informed Decision-Making**

In a review of the patient education literature, van den Borne<sup>18</sup> noted that today patients are being asked to assume an increasing level of responsibility for self-management of personal health care. This trend has stimulated work that is directed towards developing ways of empowering patients to become equal partners along with health care professionals in the process of maintaining health and well-being.

The notion that patients and their physicians should routinely engage in "shared decision-making"<sup>19</sup> about health-related issues is indicative of a paradigm shift in the physician-patient relationship. The shared decision-making paradigm, which defines the physician and patient as co-participants in a process of managing personal health and well-being, has largely supplanted the more traditional model in which the medical practitioner assumes most of the responsibility for choosing a health care strategy that is in the best interests of the patient.

There are a number of obstacles to achieving the ideals of shared decision-making. First, patients vary in terms of their familiarity with medical terminology, beliefs about health and illness, and readiness to consider multiple alternatives. Second, research has sug-

gested that patients generally want to receive as much information as possible about options available to them.<sup>20,21</sup> However, in contrast to the desire for information, there appears to be great variation in the extent to which patients wish to be involved in treatment decisions.<sup>22,23</sup> Many patients still view physicians as experts who can give them the "right decision" that should be made to resolve uncertainties in health care. Such patients may perceive active personal involvement in the process of choosing among options to be inappropriate or irrelevant and may refuse to play an active role in decision-making. Second, it is important to consider how information should be presented; patients vary in terms of their familiarity with medical terminology, beliefs about health and illness, and readiness to consider multiple alternatives.

Physicians, themselves, differ in how effectively they convey complex medical information in a manner that is easily understood and level of commitment to facilitating shared decision-making. Furthermore, if a goal is to maintain patient autonomy, then it is crucial that information be presented in a way that does not serve to systematically influence patient decision-making about whether or not to opt for screening. However, there is question as to how, and whether, "nondirectiveness" can be achieved. For example, it has been suggested that simply offering someone a test implies the recommendation to accept that offer.<sup>24</sup> Alternatively, a recent study suggests that the extent to which individuals are encouraged to consider or explore different issues related to testing significantly influences decision-making.<sup>25</sup>

Other factors that serve to shape the practice environment, such as the amount of time that is available for physicians to devote to discussions of complex health care issues with patients, may further constrain the extent to which the goal of shared decision-making can be achieved.<sup>26</sup>

### **Decision Aids in Prostate Cancer Early Detection and Treatment**

To facilitate informed decision making, it is important to enable patients to recognize the importance and legitimacy of their role in medical decision-making, consider personal values and preferences related to the choices at hand, and clarify the implications of choosing from among different health care alternatives. Research is increasing on the development of decision aids that may be used to accomplish

these goals in relation to prostate cancer early detection and treatment.

In an urban community study conducted in Michigan, media announcements were used to recruit men to undergo prostate cancer screening with DRE and PSA testing.<sup>27</sup> Men completed a baseline survey questionnaire at the screening site, viewed an educational videotape, and filled out an exit survey. At baseline, African American men were significantly less knowledgeable about prostate cancer and screening at baseline than white men. Analyses of exit survey data found that there was no longer a race-related knowledge difference. These findings suggest that an educational videotape can help to minimize knowledge differences about prostate cancer and screening.

Volk et al<sup>28</sup> reported on a study concerning the prostate cancer knowledge of 160 men who were 45 to 70 years of age and who presented at a university-based family medicine clinic for scheduled office visits. Men who completed a baseline survey were randomly assigned either to a control group or an intervention group. Men in the intervention group were shown a 20-minute videotape that presented information on the pros and cons of PSA testing. Two weeks after the office visit, an endpoint survey was administered. It was determined that men in the intervention group provided more accurate responses to survey items that concerned early prostate cancer mortality rates, performance characteristics of PSA testing, and treatment-related complications compared with control group men. The authors concluded that exposure to the videotape decision aid enhanced the capacity of study participants to make an informed decision about having a prostate cancer early detection examination.

Wolf et al<sup>29</sup> published results of a study involving older adult men who presented at a primary care physician office for an outpatient appointment. Men who were exposed to a detailed description of the pros and cons of prostate cancer early detection were less likely to be interested in having an examination than those who were exposed to a brief statement that the examination was available. In another study reported in the same article, older adult men who visited a general internal medicine clinic were randomly assigned either to an intervention group that viewed a videotape, which described prostate cancer early detection in cautionary terms, or to a control group. Men in the intervention group were much less likely to have a prostate cancer early detection examination than men in the control group. It is likely that the equivocal nature of the more intensive educational

messages discouraged men from having an examination.

Myers et al<sup>30</sup> randomly assigned 413 African American men who were 40 to 70 years of age either to a minimal or enhanced intervention group. The former group received an introductory letter that invited them to visit a urology clinic to receive information about prostate cancer early detection and to decide whether to have an early detection examination (DRE and PSA testing). The latter group received the same contact plus a personally tailored educational booklet and follow-up telephone counseling related to prostate cancer early detection. At the clinic, men from both groups were provided print materials that described the pros and cons associated with prostate cancer early detection. If the participant chose to have an examination, he was asked to sign a written consent for testing. Findings from the study showed that men in the enhanced intervention group were significantly more likely than men in the minimal intervention group to make a clinic visit and have an early detection examination (51% and 29%, respectively).

In relation to preparatory education about prostate cancer treatment, Schapira et al<sup>31</sup> conducted a pretest and post-test evaluation of a videotape decision aid that was designed to assist patients considering treatment options for clinically localized prostate cancer. The study involved 32 men who were 50 to 85 years of age and did not have prostate cancer. Analyses of survey data indicated that exposure to the videotape increased participant knowledge about treatment options and possible outcomes and generated increased interest in playing an active role in treatment decision-making.

Davison and Degner<sup>32</sup> conducted a study that was designed to assess the impact of an informational decision aid on prostate cancer patient anxiety and depression and on patient role in decision making. Sixty newly diagnosed patients from a community urology clinic in Canada were randomly assigned to receive either a package of print information that included a list of questions to ask the treating physician during medical consultation (N = 30) or the information package plus an audiotape of the consultation (N = 30). Baseline and postconsultation survey measures were obtained for patient-preferred decisional role and for anxiety and depression. Findings from the analysis of survey data showed that men in both study groups chose to play an increasingly active role in treatment decision-making and had decreased anxiety and depression at 6 weeks following consultation.

In another investigation, Onel et al<sup>33</sup> identified 111 men with newly diagnosed localized prostate cancer. The men, who were 48 to 83 years of age and were patients in four physician practices, initially met with their urologists and discussed personal PSA values and biopsy and staging results. Following the presentation of treatment options, which included radical prostatectomy, radiotherapy, and watchful waiting, the men completed a baseline survey and then viewed a 45-minute videotape. The videotape provided detailed information on risks and benefits of available treatment options and described possible outcomes. Information on the videotape was tailored according to patient risk category as defined by Gleason grade (ie, 2 to 4, 5 to 7, and 8 to 10) and patient age (ie, 55 to 65 and 66 to 75 years). A postvideo survey was completed. Analyses of survey data showed that there were significant increases in patient understanding of treatment options.

### Conclusions

Decision aids for patients have taken the form of informational booklets, scripted telephone counseling, decision boards, educational videotapes, interactive videodiscs, computer programs, and Internet Web sites. They have been developed for use in relation to a variety of situations (eg, use of alpha blockers in the treatment of benign prostatic hyperplasia [BPH], surgery for BPH, adjuvant therapy for axillary node-negative breast cancer patients, antithrombotic therapy for stroke prevention in atrial fibrillation, hormone replacement therapy for postmenopausal women, and participation in clinical trials for women who are diagnosed with breast cancer).<sup>34-40</sup> Examples of decision aids that have been developed in relation to prostate cancer early detection and treatment are outlined above. In the future development and evaluation of such tools, it is important to ensure that the educational content that is provided effectively addresses issues that are relevant and salient to potential users.

Chan and Sulmasy<sup>41</sup> have conducted extensive focus group research to identify issues of concern to older adult men who are considering whether or not to have a prostate cancer early detection examination. They outlined specific content they believe to be appropriate for inclusion in decision aids. At a minimum, they recommend that men should be advised that false-positive and false-negative results may occur and that it is not known whether PSA testing reduces prostate cancer mortality. They also suggest

that information about the pros and cons of prostate cancer early detection should be provided. Myers et al<sup>42</sup> have argued that educational messages should include the follow-up of abnormal prostate cancer early detection examination results. Message content should be tailored to patient education level, perceived self-efficacy, the belief that prostate cancer screening should be addressed in a timely fashion, belief that prostate cancer can be cured, and perceived physician support.

Feldman-Steward et al<sup>43</sup> identified 56 patients who were newly diagnosed with early prostate cancer within the previous year. A survey questionnaire was mailed to the men in order to identify the most important questions that prostate cancer patients would want to have answered. A total of 93 items, which were compiled from discussions with cancer patients, well lay people, oncologists, urologists, and health care researchers, were included on the survey. Thirty-eight men (68%) responded. There was agreement among respondents that it was essential for patients to be provided information about the nature of prostate cancer and its etiology, treatment options that are available should initial intervention fail, mechanisms whereby therapeutic interventions are known to work, likely impact of treatment impact on continence and sexual functioning, and the chances of cure.

In a national survey conducted in Canada, prostate cancer patients indicated that they did not fully comprehend information that they received about their stage of disease and different treatment options and were not satisfied with the supportive care they received.<sup>44</sup> Elsewhere, Iscoe et al<sup>45</sup> advised that it would be helpful to expand the range of medical care topics for discussion to include standard, experimental, and complementary alternative therapies. Findings from the Canadian survey and from other studies<sup>46-51</sup> indicate that concerns related to sexual dysfunction, impotence, pain, mood, and fatigue should be addressed in educational messages concerning prostate cancer treatment and recovery.

Coley et al<sup>5</sup> have observed that the optimal way to provide effective preparatory education for informed decision-making is not yet known. Preparatory education provided in conjunction with use of tailored decision aids may be extremely useful in facilitating informed decision-making about prostate cancer early detection, treatment, and recovery. More research is needed to develop effective preparatory education messages and decision aids in the context of growing access to technologies. This effort should be

guided by a clear understanding of the concerns that men and their supportive others have about the specific situations that they face at different points along the continuum of prostate cancer care. In developing these modalities, attention should be paid to the matter of reaching patient populations that display a wide range of literacy levels and numeracy skills.<sup>52</sup> Rigorous evaluation is necessary to assess the impact of these approaches on knowledge, attitudes, behavior, and clinical outcomes. Effective preparatory education approaches and decision aids should be disseminated broadly for use by practitioners with their patients.

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# Biopsychosocial Aspects of Prostate Cancer

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*Prostate cancer early detection choices and treatment options are fraught with controversy. To update the consultation-liaison psychiatrist who works with at-risk men, the authors reviewed all pertinent citations in the medicine database from 1966 to 1998 and in other relevant publications. Though watchful waiting for early-stage prostate cancer has no side effects, men must cope psychologically with issues of long-term cancer survivorship. Men can choose between different treatment options (e.g., radiation vs. radical prostatectomy) with early detection. Urinary incontinence, sexual dysfunction, and fatigue are major emotional and physical stressors for this population. Consultation-liaison psychiatrists and physicians need to be aware of the psychosocial sequelae of both prostate cancer and treatment-related side effects.* (Psychosomatics 2000; 41:85-94)

## BIOPSYCHOSOCIAL ASPECTS OF PROSTATE CANCER

Although fear, anger, confusion, and depression are common reactions to all cancers, treatment for prostate cancer means dealing with impotence and incontinence. The biopsychosocial model<sup>1</sup> is reviewed as it applies to prostate cancer.

### Epidemiology

In the United States, prostate cancer is the most frequently diagnosed non-skin cancer and the second leading cause of cancer death in men. The American Cancer Society estimates 184,500 newly diagnosed cases of prostate cancer for 1998, with 39,000 deaths. The lifetime risk of prostate cancer is about 10%. White men survive longer than African American, Hispanic, and American Indian men, but survival rates for different races are similar when corrected for grade and stage. The stage at diagnosis predicts 5-year disease-specific survival rates: local stage dis-

ease, 100%; regional stage, 94%; and metastatic disease, 31%.<sup>2</sup>

Although African American men are twice as likely as white men to get prostate cancer, African American men in Philadelphia do not perceive their personal risk of prostate cancer to be high.<sup>3</sup> Only some studies reveal differences in the frequency of digital rectal exam (DRE) screening between African American men and white men.<sup>4</sup> African American men are more likely to be diagnosed at later stages, and men 65-69 years old, with localized disease, are less likely to be treated via radical prostatectomy (RP).<sup>5</sup>

In one study, non-private patients were less likely to receive prostate-specific antigen (PSA) screening.<sup>4</sup> Lower socioeconomic groups are less willing than middle socioeconomic groups to participate in clinical trials because of

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distrust of the medical community.<sup>6,7</sup> RP is used more commonly in younger men (<60 years), and radiotherapy (RT) or watchful waiting is mostly used in older men (>70 years). Married men tend to be diagnosed earlier. Not surprisingly, survival rates are higher in married men from higher socioeconomic strata.<sup>8</sup>

Perceived discomfort of prostate screening, embarrassment, and financial cost have been identified as barriers to screening and need to be addressed by sensitive counselors.<sup>9</sup> Churches consisting of predominantly African American members, and work sites may be effective sites for prostate cancer screening and education.<sup>10</sup> Patients, particularly poorer African Americans, may opt to forgo needed care in the absence of available and affordable means of transportation to treatment facilities. Healthcare providers need to work with patients, families, and volunteer agencies in the community to enhance transportation to cancer treatment.<sup>11</sup> Although racially and culturally sensitive educational outreach programs need to provide education about prostate cancer and reduce barriers to early detection of prostate cancer among African American men, the relationship between access to care and prostate cancer outcome remains unclear.<sup>12</sup>

### BIOLOGICAL ASPECTS

#### Anatomy and Physiology

The prostate gland surrounds the urethra, and prostatic secretions make up part of the seminal fluid.<sup>13</sup> The hypothalamus secretes luteinizing hormone-releasing hormone (LHRH), which stimulates luteinizing hormone (LH) release from the pituitary. LH stimulates the testicular production of testosterone, which is turned into dihydrotestosterone, which stimulates prostatic cell growth and intracellular protein synthesis. PSA is produced both by benign and cancerous prostatic cells and released into the circulation. Prostate cancer metastasizes through blood or lymph to the pelvic nodes and then to distant sites.<sup>14</sup>

#### Staging and Grading

The TNM (Tumor, Node, Metastasis) system of the American Joint Committee on Cancer is identical to the classification system of the Union Internationale Contre le Cancer and is widely accepted. Most prostate cancers are adenocarcinomas; grade determination is based on the histopathological degree of cell differentiation and is often reported as a Gleason score (2 = very well differentiated to

10 = poorly differentiated). Lower Gleason scores are better.

#### Risk Factors

The cause of prostate cancer is unknown. Possible risk factors include African American race, increased age, family history of prostate cancer, a diet high in animal fat, and high plasma testosterone.<sup>15</sup> Occupations associated with increased risk include printers, painters, rubber workers, textile workers, mechanics, loggers, ship fitters, farmers, and drug and chemical workers.<sup>16</sup> Vasectomy and benign prostatic hyperplasia (BPH) do not appear to increase one's risk.<sup>17</sup>

Nutritional factors appear to play a role in the progression rate of prostate cancer.<sup>18</sup> Vitamin D deficiency, polyunsaturated fats, and saturated fats may increase the risk of prostatic cancer; monounsaturated fats may be protective. Selenium supplements and lycopene, an antioxidant found in tomatoes,<sup>19</sup> may lower the risk of prostate cancer. Vitamin E may reduce the incidence of prostate cancer in men who smoke.<sup>20</sup>

In rare instances, prostate cancer is inherited by autosomal dominant allele with high penetrance; 88% of carriers and 5% of noncarriers develop prostate cancer by age 85.<sup>21</sup> Men with HPC1 (hereditary prostate cancer 1) have a 90% risk of developing prostate cancer in their 90s.<sup>22</sup> Male carriers of the BRCA1 (breast cancer 1) mutation are at three times greater risk than the general population. Receiving BRCA1 results impacts on quality of life, insurance, employment, and psychosocial well-being, but the health benefits of BRCA1 testing are unknown. Currently, there are no prostate cancer screening recommendations for men who are BRCA1 carriers.<sup>23</sup>

#### Clinical Diagnosis

Many patients with prostate cancer are asymptomatic at diagnosis; others report dysuria, urinary frequency, hematuria, dribbling, decreased force of the urinary stream, incomplete bladder emptying, and/or nocturia. Metastatic disease may present with pain in the back, hips, or perineal area; bowel or urethral obstruction; or weight loss and fatigue.<sup>16</sup>

#### Screening

PSA is the most sensitive marker for prostate cancer. Uncommonly, it is possible to have a normal PSA level

(<4.0 ng/ml) and still have prostate cancer. A rise of PSA >0.75 ng/ml per year or a total PSA >4 ng/ml is associated with increased likelihood of cancer. Many men with BPH have PSA concentrations ranging from 4.1 to 10 ng/dl. Higher PSA concentrations (>10 ng/ml) have been associated with cancer as well as BPH, prostatitis, prostate infections, DRE, cystoscopy, transrectal ultrasonography, indwelling urinary catheters, transurethral resection of the prostate (TURP), and biopsy of the prostate. The clinician should aggressively investigate a PSA >10 ng/ml to rule out malignancy.<sup>24</sup>

A rising PSA level after treatment indicates recurrent disease. Lower levels of free PSA and higher levels of circulating PSA (i.e., bound plus free PSA) are more likely to be associated with prostate cancer.<sup>19</sup> Reverse transcriptase polymerase chain reaction is a highly specific research assay, which may be used in the future for staging, prognosis, and management.<sup>25</sup> The newest tests include prostate-specific membrane antigen, telomerase, and prostate markers.<sup>26</sup>

The American Cancer Society recommends annual screening with PSA and DRE for asymptomatic men over 50 who are expected to live at least 10 years longer and for men over 40 who are at higher risk. Combined abnormal PSA and DRE has a greater positive predictive value than abnormal DRE alone. Screening of asymptomatic men remains controversial (see Table 1), and the U.S. Prevention Services Task Force, National Cancer Institute, and Canadian Task Force on the Periodic Health Examination do not recommend screening.<sup>2,23,24</sup> If further testing is required after combined PSA and DRE, transrectal ultrasonography with transrectal biopsy typically follows; yet the true sensitivity of transrectal biopsy is not known. The

combined use of PSA, DRE, and ultrasound-guided biopsy may result in earlier detection, but there is no evidence from randomized trials that it reduces morbidity or disease-specific mortality. Biopsy may be associated with infection (20%), bleeding (20%), and hospitalization (<1%).<sup>15</sup>

Modifications in PSA measurement have included PSA density (serum PSA/volume of prostate gland), age-specific reference ranges, and PSA velocity (serial measurements of PSA).<sup>24</sup> Exercise and sexual activity may reduce the reliability of PSA-velocity in prostate cancer patients.<sup>27</sup> It is unclear if PSA velocity, PSA density, and age-specific reference ranges for PSA are better or not, compared to using standard PSA levels; in certain cases, however, they may provide additional information regarding early detection and treatment.

There is no way to distinguish between slow-growing tumors and clinically significant tumors.<sup>26</sup> Treatment may not reduce disease-specific mortality for tumors discovered incidentally. Although 30% of men over age 50 get prostate cancer, only 3% die from the disease. Aggressive treatment confers both morbidity and mortality.<sup>15</sup> The downside of screening is increased psychological stress with repeated testing and/or diagnosis, treatment complications, reduced quality of life, and increased costs.<sup>15</sup>

### Treatment

Treatment of prostate cancer depends on the patient's age, health, DRE, tumor stage, PSA levels, prostate biopsies, Gleason scores, and response to prior treatments for prostate cancer.<sup>28</sup> Accepted therapies include watchful waiting, RP, RT, hormonal therapy, orchiectomy, and anti-neoplastic drug therapy. There is no consensus regarding the relative survival benefits of different treatment modalities (see Table 2).

Localized prostate cancer may be managed by watchful waiting or may be treated with RP or RT. There are few published data on mortality in prospective, population-based studies for patients treated via RP or RT.<sup>29</sup> Watchful waiting may be most appropriate for older patients with

**TABLE 1. Controversies of early detection with PSA testing**

#### Advantages

- Will detect cancer early
- May detect cancer earlier than by DRE alone
- Early treatment may improve survival and avoid cancer complications
- Will reassure patient if normal
- Will give patient options to prevent spread of disease

#### Disadvantages

- May fail to detect cancer
- May cause anxiety related to testing and receiving test results
- May subject patient to further testing (e.g., biopsy)
- May subject patient to treatment-related complications
- Cannot distinguish between tumors that need treatment and tumors that are so slow-growing that without treatment, the patient is more likely to die of other noncancer causes
- Unclear whether detection reduces disease-related mortality
- Cost and whether reimbursed

**TABLE 2. Ten-year prostate cancer-specific survival rates**

Cancer Grade	Radical Prostatectomy	Radiotherapy	Conservative Management
I	94%	90%	93%
II	87%	76%	77%
III	67%	57%	45%

Note: Data adapted from Lu-Yao and Yao, 1997.<sup>29</sup>

low-grade tumors, who have other serious medical problems that make them poor surgical candidates. In an asymptomatic patient, whose life expectancy is under 10 years, prostate cancer is unlikely to cause death. Disease progression is detected with periodic screening during watchful waiting, and treatment-related complications are avoided.<sup>30</sup> Patients may experience helplessness while not pursuing active treatment. They describe being "in limbo", waiting for their cancer to grow so that definitive treatment can begin.

RT may be used successfully for localized tumors. After treatment, a PSA level that falls below 0.5 ng/ml is associated with a better prognosis. External-beam irradiation requires visits (5 days/week for 8 weeks).<sup>31</sup> Transperineal placement of radioactive seeds under ultrasound guidance is a relatively newer treatment; the seeds are left in place and emit local radiation for a short period of time.<sup>16,29,32</sup> RT also may control pain from metastatic disease.

RP involves complete surgical removal of the prostate, seminal vesicles, ampullae of the vas deferens, the vas deferens, and the bladder cuff. One cannot compare the relative benefits of RP (which includes lymph node biopsy) vs. RT, where the extent of disease is not known.<sup>29,33</sup> Because prostate cancer progresses slowly, more than 10 years may be needed to fully compare the effectiveness of RP vs. RT.<sup>29</sup>

Both RP and RT confer similar risks: mortality (0.2%–0.3%), incontinence (0.8%–0.9%), and impotence (30%–70%) are the most common sequelae.<sup>32</sup> Urinary leakage may be more common after RP than RT. Reports of pad usage after RP vary in the literature with the majority of men having minor or no urinary leakage by 6 months. Despite the newer "nerve sparing" techniques, many men may become impotent immediately after surgery.<sup>34</sup> Postoperative potency may be related to the number of spared neurovascular bundles, frequency of intercourse preoperatively, absence of seminal vesicle or lymph node involvement with cancer, absence of postoperative incontinence or stricture, age, and cancer volume.<sup>35,36</sup> With RT, men may have a progressive loss over time in erectile function, suggesting that with time, posttreatment impotence may not differ significantly between men treated with RT vs. those treated with RP.<sup>34</sup> Gastrointestinal problems are more likely to be seen after RT.<sup>31</sup>

Locally advanced disease is treated with combinations of RP, RT, and hormonal therapy.<sup>16,29</sup> Before surgery or RT, hormones may be used to reduce tumor size or to downstage the cancer. RT may be used with local tumor

recurrence. If PSA is elevated post-RP, therapeutic irradiation can achieve a complete response (PSA <0.1 ng/ml) in up to 80% of patients.<sup>37</sup>

In advanced prostate cancer, therapy is aimed at disease control rather than cure. Asymptomatic patients may choose watchful waiting. Although hormonal treatment is preferred in symptomatic patients, it may not increase survival. Hormonal therapies include orchiectomy, estrogen use, or chemical castration via LHRH agonists. Bilateral orchiectomy removes 95% of serum testosterone and is a minor, low-cost procedure that eliminates the need for daily medication. Metastatic pain may be relieved within hours or days. Side effects include loss of libido and impotence. The psychological impact of orchiectomy may preclude the choice of this treatment option.<sup>16,32</sup>

Orchiectomy may cause feminization, gynecomastia, redistribution of fat, loss of facial hair, sterility, and/or reduced libido.<sup>38</sup> Montgomery and Santi<sup>39</sup> noted significant differences in physical self-concept and identity before and after orchiectomy. Postoperatively, patients felt greater negativity in physical appearance, state of health, and sexuality. Patients expressed identity concerns and feared that a reduction in masculinity might lead to personality changes. Profound symbolic loss (as well as physical loss) after orchiectomy is experienced if the man associates his testicles with male strength, virility, and power.<sup>39</sup> The psychological effects of orchiectomy may be reduced with insertion of testicular prostheses.<sup>40</sup>

Diethylstilbestrol (DES) reduces testosterone by negative feedback on LH. Daily therapy is required, and side effects include nausea, vomiting, fluid retention, headache, impotence, reduced libido, gynecomastia, and increased cardiovascular risk, including thromboembolic complications. Recently, LHRH analogues are replacing DES.<sup>16</sup>

LHRH analogues (e.g., leuprolide, goserelin) are taken daily or via long-acting injections and cause constant pituitary stimulation by occupying the LHRH receptors. Initially, they increase testosterone release, inducing tumor growth; if the tumor is located in the spinal cord, this growth can cause spinal cord compression. Side effects include impotence, loss of libido, and hot flashes.<sup>16,32</sup> Concomitant use of an antiandrogen for the first 2 weeks of treatment may prevent the testosterone surge. Antiandrogens block androgen receptors and are either steroidal (progestin) or nonsteroidal (flutamide, nilutamide, bicalutimide). Total androgen blockade may be achieved using a combination of orchiectomy and/or antiandrogens. Androgen deprivation causes hot flashes, loss of libido, impotence, and decreased muscle mass.<sup>16,32</sup> In hormone-refractory cancers,

various therapies including antineoplastic agents are used, with most agents showing poor response. Combination therapy may slow disease progression and increases survival compared to monotherapy, but this is controversial.

Hormonal castration usually tends to improve depression in patients with prostate cancer. As there is no threatened loss of body parts, patients describe feeling whole again and "embodied."<sup>41</sup> However, increased depression also has been observed in some patients on hormonal therapy, perhaps linking depression to decreased testosterone. As one study has described depression secondary to leuprolide treatment in patients who had metastatic prostatic cancer, screening for depression may be warranted.<sup>42</sup>

In advanced cancers, pain control should be assessed. Methods to control pain include wraps, pressure stockings, and heat in addition to opioids, steroids, nonsteroidal anti-inflammatory agents, antidepressants, and psychological support.<sup>16,32</sup> Treatment, side effects, and quality-of-life (QOL) concerns often influence patients' decision-making regarding early detection and treatment.

### PSYCHOLOGICAL ASPECTS

Patient education regarding screening is needed, since screening results in a high probability that further testing, treatment, and treatment-related decision-making will be necessary, particularly in high-risk groups.<sup>26</sup> If the patient has male relatives with prostate cancer, he may want a genetic test to determine his risk for prostate cancer.<sup>43</sup> Although African American men in Philadelphia are receptive to annual screening,<sup>4</sup> there are still misconceptions about DRE (e.g., is something being inserted that will compromise [their] masculinity?). In one study, patients of low socioeconomic status showed less interest in PSA screening after informed consent. Videotaped educational interventions enhance patient knowledge and allow physicians to discuss more sophisticated patient concerns.<sup>44</sup> Faced with the diagnosis of a deadly disease, men simultaneously must confront threats to their sexuality and masculinity. Building rapport and trust during initial visits allows men to share their concerns. Survivors of prostate cancer must deal with treatment-related complications in the context of other age-related losses: health, energy, retirement, and deaths of peers and family members.

Patients with prostate cancer face several barriers to receiving appropriate psychiatric intervention. Cancers with sexual associations carry greater social stigma. North American men generally do not seek psychiatric help and tend to use mental health services less than women. Older

men may be less likely to agree to psychiatric evaluation or treatment and are unlikely to report emotional distress. Physicians tend to underestimate the psychological comorbidity of prostate cancer patients, and patients with subsyndromal psychiatric symptoms may remain untreated, even after identification. A paper thermometer scale to screen for psychological distress in prostate cancer patients, who might need psychiatric referral, detected a high degree of distress (32.6% anxiety and 15.2% depression). However, 40% of the distressed men missed or refused their psychiatric interview. Over half the men identified failed to meet the criteria for a psychiatric diagnosis.<sup>45,46</sup>

Although there is increasing emphasis for men to assume a more active role in treatment decision-making, not all men may be comfortable with this role. Davison and Degner<sup>47</sup> studied whether improved information acquisition and assuming a more active role in treatment decision-making would lead to decreased anxiety and depression in men with newly diagnosed prostate cancer. Sixty newly diagnosed men with prostate cancer were randomized to receive either an intervention that consisted of written information with discussion, a list of questions to ask their physician, and an audiotape of the medical consult, or written information alone. At 6 weeks postintervention, lower state anxiety scores on the Spielberger State-Trait Anxiety Inventory were observed for the intervention group. The Center for Epidemiologic Studies Depression Scale (CES-D) did not reveal significant differences between the two groups.<sup>47</sup>

### Anxiety

Between 25% and 47% of cancer patients suffer from psychiatric syndromes. Reactive anxiety is the most common reason for psychiatric referral of cancer patients. Prostate cancer patients may react to the PSA test with anxiety, either before obtaining the test or while awaiting test results.<sup>48</sup> The degree of anxiety and depression experienced by cancer patients (prostate included) was not measurably different between different cancer sites (i.e., prostate, gynecologic, breast, lung, brain, colon, head and neck, hepatoma, and lymphoma) on the Brief Symptom Inventory.<sup>49</sup>

Screening for prostate cancer is marked by increases in psychological stress and serum cortisol levels. The highest cortisol levels are detected 2 weeks after biopsy, just prior to being informed of the biopsy results. Even patients who were told that their biopsies were benign had elevated cortisol levels. Cortisol levels subsequently decreased to

normal baseline values. Prostate cancer patients noted a lag in sleep disturbance, correlating with increased anxiety, 2 weeks after they were given their results.<sup>50,51</sup>

Posttraumatic stress disorder (PTSD)-related symptoms also have been reported in prostate cancer patients.<sup>52</sup> Patients may reexperience the traumatic events in dreams, disturbing recollections, and flashbacks.<sup>53</sup> Risk factors such as poor social support, a history of traumatization/victimization, or previous psychiatric disorder may predispose certain patients to PTSD. Cancer treatments are frequently intrusive and painful. Patients may feel a loss of control or experience helplessness in the face of life-threatening disease. In long-term cancer survivors, repeated treatments and/or recurrences may act as a series of stressors. While 25%–33% of all people who experience traumatic events develop PTSD, in one study, 4% of female cancer survivors had PTSD.<sup>54</sup> Although no specific PTSD treatment has been proposed for cancer patients with PTSD, cognitive-behavioral therapies and support groups may be beneficial.

Kornblith and colleagues<sup>52</sup> studied 173 men with prostate cancer and 83 spouses/partners, using the Intrusion Subscale of the Impact of Event Scale and Selby's Quality of Life Uniscale. Both patients and spouses reported frequent intrusive thoughts and images. Spouses reported greater psychological distress than the patients. Prostate cancer patients exhibited no relationship between treatment severity or intensity and intrusive or avoidant symptoms.

Clark and colleagues<sup>55</sup> studied quality-of-life issues in men with metastatic prostate cancer and identified three key domains: self-perceptions; anxiety about the effects of treatment; and concerns about treatment decision-making. Many of the men reported anxious preoccupation or developing a fighting spirit in the face of their disease. Relationships with wives were altered. Though issues of intimacy and affection were troublesome for some men, impotence was emotionally distressing for most men. It was both difficult and comforting for spouses to emphasize emotional companionship. Body image, sexual problems, spouse affection, spouse worry, masculine image, cancer-related self-image, cancer distress, cancer acceptance, and regret over previously made decisions were areas of concern, particularly in men who had experienced many side effects.<sup>55</sup>

### Depression

Some sadness is not unusual when patients are diagnosed with prostate cancer. Physicians must distinguish be-

tween "normal" sadness in response to the cancer diagnosis and clinically significant depression.<sup>56,57</sup> Issues such as cancer stage, clinical course, type of treatment, and presence of pain must be considered in evaluating depression.<sup>58</sup> Although 20%–25% of all patients with cancer may have a depressive disorder, depression often goes unrecognized. Neurovegetative symptoms may be due to the cancer or to the depression. Symptoms that differentiate the depressive illness from cancer include a sense of failure, social withdrawal, feelings of being punished, suicidal ideation, dissatisfaction, and indecision. Loss of interest and crying may present with more severe depression. Risk factors for depressive disorders include social isolation, recent losses, a tendency to pessimism, socioeconomic pressures, previous mood disorder, alcohol or substance abuse, previous suicide attempt, poorly controlled pain, depressive side effects of medication, and metastatic cancer. Psychotherapy, psychopharmacology, psychoeducation, and electroconvulsive therapy are all effective treatments for cancer patients with depression. Antidepressants with significant anticholinergic side effects should be avoided in patients with urinary retention or reduced intestinal motility.<sup>56,57,59,60</sup>

Most individuals associate cancer with a slow, painful death.<sup>61</sup> Patients with pain are more likely to suffer depression and anxiety, and Heim and Oei<sup>62</sup> found that 55% of patients with prostate cancer reported pain. Analgesic drugs with lower side-effect profiles should be combined with adjuvant pharmacologic (e.g., antidepressants) and nonpharmacologic strategies, particularly in older patients.<sup>63,64</sup>

### Adjustment to Treatment-Related Side Effects

Physicians may underestimate the degree of emotional distress related to reduced libido, feeling unattractive, impotence, and incontinence. Although most impotence is treatment-related, for some men, psychogenic factors may be partly responsible, and psychiatric intervention may be important.<sup>65</sup> In the past, as most older adult men passed the traditional age associated with raising a family, less attention was paid to erectile function and the psychological consequence of impotence. However, older men are as likely to be disturbed by postsurgical impotence as younger men.<sup>66</sup> Etiology of erectile dysfunction after prostate cancer therapy is probably multifactorial. Arteriogenic impotence predominates among men undergoing RT. Venocclusive/cavernosal pathology predominates among men undergoing RP. Although most patients report problems in

sexual/urinary function, global quality of life does not appear to be compromised after RP.<sup>67</sup>

Despite complaints of difficulty with erections, 60% of impotent patients did not use erectile aids (e.g., injections, vacuum devices) for 12 months or longer post-RP. Although impotency was a principal concern, most stated they would undergo surgery again for their peace of mind.<sup>66</sup> Sildenafil citrate (Viagra<sup>®</sup>) can reduce erectile dysfunction. It is administered orally, once daily, and is less invasive compared to cavernosal injection and implantation of penile prostheses. According to the manufacturer, 43% of men who had erectile dysfunction after RP achieved adequate sexual function with sildenafil citrate.<sup>68</sup> Men have to be sexually aroused for the drug to be effective. Side effects of sildenafil citrate include headache, flushing, dyspepsia, and visual disturbances. The use of organic nitrates is absolutely contraindicated in patients taking sildenafil citrate. Sixty-nine deaths have been associated with sildenafil citrate: 46 had cardiovascular events; 21, unknown; and 3 had strokes.<sup>69</sup>

Men suffering from prostate cancer report impotence, fatigue, and incontinence as their primary concerns. Fatigue may be worsened by the increased demands of going for office visits and to the pharmacy. Incontinence (i.e., urine leakage, smelling of urine, and having to wear pads) leads to related demands to do more laundry and increased planning to be able to participate in social activities. After RP, some men may occasionally lose a few drops of urine when lifting heavy objects or coughing (i.e., stress incontinence). Other men are left with very little control over urine flow. Social isolation and embarrassment are understandable consequences.

### SOCIAL ASPECTS

Until recently, prostate cancer had not received the same attention as other cancers in the popular press. Despite increasing numbers of published personal accounts of prostate cancer, the stigma of having cancer and potentially impaired sexuality may prevent patients from seeking adequate social and psychological support. Furthermore, there may be confusion between BPH and prostate cancer, leading men to underestimate the seriousness of the disease.

Men with prostate cancer receive assistance with household matters, emotional support, and encouragement from their spouses. However, spouses (and partners) show greater psychological distress than their husbands do, and this distress increases as the patient's condition worsens. It

is unclear if this reflects gender differences in reporting or truly greater stress induced by repeatedly witnessing intrusive, invasive, and painful treatments of a loved one while dealing with anticipatory bereavement.<sup>52</sup> One study suggests that wives prefer early detection strategies for their spouses that offer increased survival at the expense of quality of life. Decision-making strategies clearly vary among couples.<sup>8,70</sup>

Social support is positively correlated with psychological well-being, and low levels of social support correlate with increased mortality from all causes. Emotional support enhances self-esteem; informational support may provide advice or cognitive guidance. Social companionship provides contact with others and may provide a needed distraction from the stress of having cancer. Instrumental support can meet concrete needs by providing financial aid or material resources. Involvement in a social network can contribute to well-being by helping to develop feelings of predictability and stability. Social support buffering mechanisms for men are met through friendship, reassurance of worth, and reliable alliances. Companionship and task accomplishment adds to satisfaction. These social supports may translate into health benefits by positive influences on the functioning of neuroendocrine or immune systems, thereby acting as a buffer against disease. Other positive health-related effects include positive influences on behavior patterns (e.g., smoking and alcohol use).<sup>8,59,70,71</sup>

Although it seems obvious that families caring for patients with prostate cancer are under emotional, physical, and financial strain, literature on prostate cancer caregivers is not available. Difficulties in communication and delays in care may result from inadequate knowledge or reluctance to ask about urologic needs or sexual symptoms. Dysfunctional and difficult families may find caregiving particularly overwhelming. Competent psychosocial intervention may help.<sup>47</sup>

National support groups, such as "Us Too" and "Man to Man," can help meet the emotional and educational needs of prostate cancer patients.<sup>71</sup> Interviews of some group members of Us Too and their primary care physicians revealed that although a high percentage of physicians recall discussing treatment options, side effects, and costs, a very low percentage of patients recall having had the same discussions. However, over 90% of both physicians and patients felt that the patient's own primary physician was a good source of cancer-related information. Both patients and physicians felt that physicians are less likely to provide emotional support. Support groups can

address unmet emotional and educational needs of prostate cancer patients and minimize suffering.<sup>72-74</sup>

Unfortunately, most survey instruments used to measure quality of life have not been standardized in this population, and complete data relating to QOL are absent in the literature. Reliable questionnaires that are prostate cancer-specific are being developed; however, physical function, pain, social activity, and sexual function are the most important areas of concern.<sup>75</sup> Most QOL studies include physical functioning, activities of daily living, and patient-reported sense of well-being. There have been some reports of physician resistance to measuring QOL. There is no consistency between which factors were measured by different instruments. QOL researchers suggest that problems in adaptation are seen most often in late-stage patients, who report greater pain, fatigue, and urinary difficulties.

Physicians often overestimate the level of physical functioning of a patient. Decreased sexual functioning, urinary incontinence, and bowel symptoms need to be considered in evaluating QOL. Some men trade long-term survival for potency; others avoid decreased sexual potency at all costs. Personality, motivation, a strong support system of family and friends, favorable environmental factors such as living in a first-floor apartment, having access to a pharmacy and other stores, and appropriate medical care are all important determinants of QOL.<sup>52,76-79</sup> Some indicators that are used to measure QOL are body image, sexual problems, spousal affections, spousal worry, masculinity, cancer-related self-image, cancer distress, cancer acceptance, and regret of treatment decisions.<sup>80</sup> Self-perceptions, anxiety regarding treatment effects, and decision-making are equally important domains. Preservation of QOL at the expense of survival requires a clear understanding of what this trade-off entails.<sup>81</sup> Quality-adjusted survival rates may not be appropriate to use in determination of treatment plans because of variations in individual values. It may be unreasonable to base treatment expectations on a return to the patient's premorbid level of functioning.

Because there is no therapy that is clearly superior for all patients and because all treatments carry risks of side effects, QOL considerations become increasingly impor-

tant in decision-making models. Often patients are faced with complex decisions that need to be made within a moderate time frame and for which patients are ill-prepared. Recent studies have attempted to incorporate educational programs into standard office visits. Determination of patient treatment preferences, using various decision-making aids, may facilitate decisions regarding early detection and treatment.<sup>82</sup> Development of screening and treatment programs is hindered by lack of consensus regarding optimal methods of detection and treatment for prostate cancer. Even Medicare does not reimburse PSA screening. One study of 21 large managed care organizations indicated that they felt PSA testing was not mandatory; no treatment policy was in place for any of the managed care companies surveyed.<sup>83</sup>

### CONCLUSION

Men undergoing early detection for prostate cancer experience uncertainty related to the time course of cancer and often fear treatment and treatment-related side effects. It is still unclear whether early detection can reduce disease-specific mortality, and therein lies the controversy about early detection. Healthcare providers need to consider patient and family beliefs in the context of ethnocentric values. Although most patients are able to adapt to the cancer diagnosis and its management, QOL and treatment complications should be discussed by physicians who can counsel patients in the selection of preferred courses of treatments. Treatment choices are made more difficult by the lack of information on the long-term relative effectiveness of RP vs. RT.

Ideally, the management of anxiety and depression requires a multidisciplinary and multimodal approach. Psychiatrists can assist as diagnostic consultants in monitoring adjuvant psychotropic medications and in providing appropriate psychotherapy for treatment for men with prostate cancer and their families. An understanding of the current controversies in early detection and treatment can assist the C-L psychiatrist in working through difficult medical decisions with their patients.

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# African American Men, Prostate Cancer Early Detection Examination Use, and Informed Decision-Making

Ronald E. Myers

It is well known that African American men are more likely to be diagnosed with metastatic prostate cancer than White men. Racial variation in the use of prostate cancer early detection modalities (ie, digital rectal examination [DRE] and prostate-specific antigen [PSA] testing) has been suggested as a major reason for this differential. Several factors may help to explain the reported low levels of DRE and PSA test utilization among African American men, including background sociodemographic characteristics, medical history, and cognitive and psychosocial perceptions. In this review, the impact of these characteristics on prostate cancer early detection examination utilization is explored. Findings from studies showing race-related differences in cognitive and psychosocial factors are presented. Preparatory education for informed decision-making is suggested as an approach to help minimize racial differences in cognitive and psychosocial factors that influence the use of prostate cancer early detection modalities. The need to facilitate informed decision-making along the continuum of care is highlighted. *Semin Oncol* 26:375-381. Copyright © 1999 by W.B. Saunders Company.

**P**ROSTATE CANCER is the most frequently diagnosed cancer and is the second leading cause of cancer death among men. It is estimated that in 1999, there will be 179,300 new cases of prostate cancer and an estimated 37,000 deaths from the disease in the United States.<sup>1</sup> One in six men will be diagnosed with prostate cancer during their lifetime. Most men who are newly diagnosed with prostate cancer will have the disease detected by a prostate cancer early detection examination. The prostate cancer early detection examination usually includes both a digital rectal examination (DRE) and prostate-specific antigen (PSA) test. Abnormal results are often followed by a transrectal ultrasound and biopsy.

Incidence rates (per 100,000) for prostate cancer are substantially higher for African American men than other racial and ethnic groups in the United States (African American, 224.3; White, 150.3; Hispanic, 104.4; Asian/Pacific Islander, 82.2; American Indian, 46.4). The mortality rate for this disease is also dramatically higher among African American men versus other groups (African American, 55.0%; White, 24.1%; Hispanic, 16.8%; Asian/Pacific Islander, 10.9%; American Indian, 14.2%). Further, across all stages of prostate cancer, African

American men have relatively low 5-year survival rates compared with White men (81% v 95%, respectively).<sup>1</sup>

Racial variation in the utilization of prostate cancer early detection modalities (ie, DRE and PSA testing) has been observed. More specifically, African American men appear less likely to have a DRE and PSA test in the absence of symptoms than White men.<sup>2-7</sup> As a result, African American men are more likely to be diagnosed with metastatic disease.<sup>8,9</sup>

## FACTORS THAT MAY INFLUENCE PROSTATE CANCER EARLY DETECTION EXAMINATION USE

Health behavior theory suggests a number of factors that may influence the utilization of cancer early detection modalities such as the DRE and PSA test.<sup>10-12</sup> These factors include personal background (eg, sociodemographic characteristics and medical history), cognitive and psychological representations, social support and influence, intention to engage in preventive behavior, and exposure to educational programs, and help to predict actual preventive behavior. On a personal level, background may be defined in terms of age, gender, race, income, education, marital status, and medical history. Each of these characteristics subsumes an underlying experiential frame of reference that conditions individual perceptions of health-related stimuli encountered in everyday life. Cognitive and psychological representations are the perceptions of specific health threats, procedures that are available for coping with the threat, and outcomes that are likely to result from coping efforts. One's view of the threat is shaped by cognitive notions related to susceptibility or risk, severity, cause, and curability of disease, along with the emotional

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reactions that such notions elicit. Individuals also consider the procedure(s) that may be used to cope with an acknowledged health threat in terms of technical effectiveness, practical convenience, personal benefit, and importance to well-being. Social support and influence are factors that refer to the individual's perceptions about the stance that significant others have taken or are likely to take in relation to the threat or the procedure(s) that are available to cope with the threat. Self-reported intention signals the extent to which the individual is oriented toward engaging in a given coping behavior. Further, exposure to behavioral prompts or interventions by health care providers can serve as a strong, direct prompt to behavior. Relatively little research has been performed to identify possible predictors of prostate cancer early detection use among African American men.

#### **PERCEPTIONS RELATED TO EARLY DETECTION EXAMINATION AMONG AFRICAN AMERICAN MEN**

In a community-based investigation in Florida, Smith et al<sup>13</sup> conducted face-to-face interviews about prostate cancer early detection with 556 African American men aged 40 years or older. Sixty-nine percent of the men were 50 and older, 18% had more than a high school education, and 48% were married. It was found that 91% of the men believed that prostate cancer can be cured. Two thirds of the respondents thought a man can have prostate cancer without having any symptoms. However, only 58% felt it was necessary to have an early detection examination in the absence of symptoms. In terms of susceptibility, just 42% of the participants believed that family history confers increased risk, and fewer than one third thought that African American men have a higher risk of prostate cancer than White men.

Myers et al<sup>14</sup> conducted a study to identify factors associated with intention to have a prostate cancer early detection examination among African American men. Telephone survey data were obtained from 218 African American men who were 40 to 70 years of age. Men in the study were randomly selected from the patient population of a large primary care practice in Philadelphia. Forty-three percent of the men were 50 years of age or older, 41% had more than a high school education, and 65% were married. Almost two thirds of the respondents perceived the risk of prostate cancer

among African American men to be high. However, only 30% rated their personal risk for prostate cancer as high. Fifty-nine percent of the men viewed having an early detection examination to be a salient and coherent preventive health behavior, and 58% considered it to be efficacious. A substantial proportion of survey participants (41%) expressed concern about DRE-related discomfort and embarrassment, 63% were worried about having an abnormal early detection examination result, and 18% believed that having an early detection examination might cause them to have sexual problems. Forty-three percent of the men were also concerned about the financial expense of an early detection examination. In terms of social support, 55% of the respondents believed that their physicians and significant others would encourage them to have a prostate cancer early detection examination. Study participants were asked to indicate whether they intended to have a prostate cancer early detection examination in the future. Sixty-nine percent reported that they intended to do so. Multivariate analyses showed that perceived examination efficacy and physician support for early detection were significantly associated with the intention to have an early detection examination.

#### **PREDICTING EARLY DETECTION EXAMINATION USE AMONG AFRICAN AMERICAN MEN**

Recently, Myers et al<sup>15</sup> concluded a randomized trial of an educational intervention designed to encourage African American men to present at a urology clinic for prostate cancer education and early detection. Baseline telephone survey data were collected for 413 study participants in Chicago who were 40 to 70 years of age. The men were then randomly assigned to either a minimal or enhanced intervention group. Men in the former group were mailed an introductory letter that invited them to the clinic and a reminder letter. Men in the enhanced intervention group received the same correspondence and were provided a personalized educational booklet plus a telephone call that was designed to highlight educational messages included in the booklet. At the clinic, men were required to complete an informed-consent form prior to having an early detection examination.

At baseline, 59% of the study participants

believed that African American men are at increased risk for prostate cancer compared with White men. However, only 14% of the respondents thought they themselves had a high risk for developing prostate cancer and 19% were worried about being diagnosed with the disease. Most (86%) believed that prostate cancer can be cured and that men should have an early detection examination before symptoms occur (79%). Men in the study tended to believe that prostate cancer early detection is salient and coherent preventive health behavior (89%), the early detection examination is efficacious (92%), and early detection has a positive impact on well-being (95%). Many of the men also expressed concern about examination-related physical discomfort and embarrassment (45% and 48%, respectively); and one fifth of the men believed that having an early detection examination can cause health problems. Most respondents believed that their primary care physician and family members supported prostate cancer early detection. (70% and 76%, respectively).

Results of multivariate analyses showed that men who were assigned to the enhanced intervention group were significantly more likely to schedule and keep a clinic appointment than men in the minimal intervention group (51% and 29%, respectively). All but one of the men who presented for an appointment chose to have an early detection examination. Other significant predictors were older age (>50 years), married status, the belief that one should have a prostate cancer early detection examination before symptoms occur, and self-reported intention to have an examination.

Elsewhere, Tingen et al<sup>6</sup> studied the response of African American men to an educational program that was offered through various community sites (eg, worksites, churches, housing projects, and barbershops) in central South Carolina. The program included information on prostate cancer, a description of the American Cancer Society guidelines for DRE and PSA test utilization to detect early prostate cancer, and educational messages that strongly promoted routine use. Some men (n = 343) received the program as a standard intervention. For others (n = 259), the standard intervention was supplemented by a testimonial about prostate cancer early detection provided by a peer. Still other men (n = 294) received the standard program plus a reminder telephone call from a social worker. Finally, some men (n = 315)

were provided the standard intervention plus both the testimonial and reminder telephone call. All program attendees were provided a voucher to take to a primary care physician for a free DRE and PSA test. Mailed reminders were also used to encourage adherence to prostate cancer early detection. Base-line survey measures (ie, age, education, income, prior DRE and PSA test use, and exposure to intervention) were examined in multivariate analyses of adherence to prostate cancer early detection. Results of these analyses showed that men who were older and who received either the testimonial or the telephone call reminder were significantly more likely to have a prostate cancer early detection examination. Intervention effects were as follows: standard intervention, 52%; standard intervention and testimonial, 59%; standard intervention and telephone call, 66%; and standard intervention plus testimonial and telephone call, 68%.

Elsewhere, Powell et al<sup>16</sup> showed that a community-based educational program involving African American churches was successful in encouraging prostate cancer early detection among men who were 40 to 70 years of age. The program involved a presentation by African American physicians and prostate cancer survivors at the church. Following the presentation, medical staff were on hand to collect serum samples for use in PSA testing. During the course of 1 year, more than 1,000 men who attended one of the church-based presentations decided to have a PSA test.

The summarized findings show that measures of background, cognitive and psychological representations, social support and influence, and exposure to educational interventions can be used to identify African American men who are likely to choose to have and not to have a prostate cancer early detection examination. In this regard, being older, believing that one should not wait for symptoms before undergoing an early detection examination, having faith in the efficacy of the examination process, and having trusted lay and professional support for early detection are factors that seem to predispose men to take preventive action. Only a limited amount of research on racial variation in such predictors has been reported.

#### **RACE AND FACTORS RELATED TO PROSTATE CANCER EARLY DETECTION**

Demark-Wahnefried et al<sup>17</sup> reported the results of a survey administered to 1,504 men who pre-

sented for DRE and PSA testing at nine southeastern sites that participated in the 1992 National Prostate Cancer Awareness Week. Survey findings showed that African American men tended to have less formal education and were less likely to be married than White men. African American men were more likely to report health problems but less likely to have a primary care physician. Fewer African American men indicated that they had ever had a DRE or PSA test. In relation to perceptions about prostate cancer and early detection, African American men were less likely than White men to report that they knew someone who was diagnosed with prostate cancer to believe that "a man with prostate cancer can have a normal life," and to know that "men can have prostate cancer without symptoms." African American men were more likely to believe that prostate cancer treatment causes impotence.

McCoy et al<sup>18</sup> administered a telephone survey to 897 men in Florida. The men identified themselves in terms of race/ethnicity as follows: 271 (31%) African American, 284 (33%) White, and 314 (36%) Hispanic. African American men in the sample tended to have less formal education than either White or Hispanic respondents. Both African American and Hispanic respondents had lower levels of income than White respondents. In addition, fewer African American and Hispanic men reported ever having a DRE as compared with White men. African American and Hispanic men were also more concerned about examination-related discomfort and embarrassment than White men. The authors reported that African American men tended to be more pessimistic about the prospects of curing prostate cancer as compared with White and Hispanic men.

Weinrich et al<sup>7</sup> collected and analyzed baseline survey data for 319 (33%) men who attended a community-based educational presentation about prostate cancer early detection and reported never having a DRE or PSA test. Of this number, 260 (82%) were African American. The African American attendees, as compared with White attendees, had less formal education, a lower level of income, and less knowledge about whether they had a family history of prostate cancer, and were more likely to report having pain in the lower back, hips, thighs, testicles, or rectum during the prior year. Similar results were reported for analyses that were performed within community sites.<sup>19,20</sup>

Findings of the studies reported here suggest that African American men, as compared with White men, tend to have less knowledge about prostate cancer, less favorable views about early detection and the consequences associated with treatment, and less social support for taking preventive action. Educational interventions of the type described earlier may serve to effectively minimize racial differences in cognitive and psychosocial factors associated with DRE and PSA test use. As a consequence, their use may increase the proportion of African American male prostate cancer patients who have an early detection examination and are diagnosed with early disease. However, it is important to point out that current controversies about prostate cancer early detection and treatment require close consideration of educational intervention goals.

#### CONTROVERSIES ABOUT PROSTATE CANCER EARLY DETECTION

Proponents of prostate cancer screening observe that combined DRE and PSA testing is effective for identifying men with early prostate cancer, and that men who are diagnosed with and treated aggressively for localized prostate cancer have higher survival rates compared with men diagnosed with late-stage disease.<sup>21,22</sup> Further, it has been argued that the use of DRE and PSA testing is justified for asymptomatic older men who have a reasonable life expectancy and are at increased risk (ie, African American men and men with a family history of prostate cancer).<sup>23,24</sup> The American Urological Association<sup>25</sup> and American Cancer Society<sup>26</sup> suggest that men aged 50 years or older with a life expectancy of at least 10 years should be offered DRE and PSA testing on an annual basis.

However, caution has been urged regarding the routine use of DRE and PSA testing for prostate cancer early detection, because no randomized trials have demonstrated that early detection can reduce mortality from prostate cancer.<sup>27,28</sup> Unfortunately, results of randomized trials designed to answer this question will not be available for a number of years.<sup>29-31</sup> Concern about prostate cancer early detection is also based on the fact that the treatment of early-stage prostate cancer can cause substantial adverse outcomes (eg, impotence, incontinence, stricture, bowel injury, and death).<sup>32,33</sup> Guidelines proposed by the US Preventive Services Taskforce and the Canadian Taskforce on the

Periodic Health Examination recommend that DRE and PSA testing should not be performed to screen for early prostate cancer.<sup>34,35</sup> The American College of Physicians has recommended against routine prostate cancer screening among older adult men, and has suggested that men be advised about the potential benefits and harms of prostate cancer early detection prior to examination performance.<sup>36</sup>

The differences of opinion summarized here highlight the need for informed decision-making regarding prostate cancer early detection. It is especially important to develop approaches that can be used to prepare African American men to decide whether to have an early detection examination, given the extraordinary burden of prostate cancer in this population group.

#### PREPARATORY EDUCATION FOR INFORMED DECISION-MAKING

Myers et al<sup>15</sup> showed that a personally tailored package of print materials and telephone contacts can have a strong effect on the adherence behavior of African American men. In their study, a "two-step" educational intervention process was used. That is, men were initially encouraged to make an office visit to obtain information about prostate cancer and to decide whether to have an examination. Then, at the visit, informed consent was obtained before an early detection examination was performed. Once the men responded to the intervention by making an office visit, exposure to the informed-consent process made no difference in whether they had an early detection examination.

Flood et al<sup>37</sup> reported similar results in a study that involved men who presented at a medical clinic to have a prostate cancer early detection examination. In that investigation, men were randomly assigned to view either a videotape that described prostate cancer, early detection, and treatment consequences or a videotape that encouraged having an examination. No difference in adherence to the examination was observed in the two groups. It is important to note that the results of their study pertain to men who came to a clinic ready to consider having an early detection examination. It may be that among these men, the in-office presentation was viewed as reinforcing the decision to have an examination. Alternatively, men who visited the office may not have

fully attended to or understood the informational content at hand.

Findings from other studies in the area of decision-making about prostate cancer early detection support the view that more cautionary educational interventions are likely to decrease the interest in having a PSA test among men who have not yet considered having an early detection examination. Wolf et al<sup>38</sup> reported the results of a study involving men who presented at a primary care physician office for an outpatient appointment. Men who were exposed to a detailed description of the pros and cons of prostate cancer early detection were less likely to be interested in having an examination than those who were exposed to a brief statement that the examination was available. In another study reported in the same article, older adult men who scheduled a visit at a general internal medicine clinic were randomly assigned to view a videotaped presentation that described prostate cancer early detection in cautionary terms versus no videotape. Men in the former group were much less likely to have a prostate cancer early detection examination than men in the latter group. It is likely that the equivocal nature of the more intensive educational messages discouraged having an examination.

Population background and cognitive and psychosocial factors should be considered in organizing educational programs intended to influence attitudes and behavior related to prostate cancer early detection among African American men. New approaches for facilitating informed decision-making about having an early detection examination are needed. The educational content of such preparatory education methods should focus on clarifying the purpose and pros and cons of having an early detection examination. Preparatory education of this sort should aim to elicit individual values and relate personal preferences to the prospect of taking preventive action. Attention should be given to involving the significant others of at-risk men in the decision-making process.

Coley et al<sup>36</sup> have observed that the optimal way to enable people to systematically consider the available information about prostate cancer care, to weigh the pros and cons of having an early detection examination, and to make informed judgments about medical care is not known. Although "shared decision-making" has been promoted as a method for involving patients and

practitioners in this process,<sup>39</sup> Deber<sup>40</sup> has asserted that preparatory education may be needed prior to the physician-patient encounter. Preparatory education should enable individuals to engage the practitioner in the process of deciding about the personal use of available prevention and treatment alternatives. When provided early in the process of care, preparatory education can serve to facilitate interactions between informed parties, including the supportive others of the patients. Such interactions are likely to be especially helpful in areas where there is a high degree of uncertainty regarding potential consequences.

Ubel<sup>41</sup> has observed that although a variety of methods (eg, printed and verbal descriptions of behavioral alternatives, decision boards, videos, and interactive videodiscs) have been used to make information about prostate cancer early detection available, little is known about their impact on the knowledge, attitudes, and beliefs of asymptomatic men who are in the position of having to decide whether or not to have an early detection examination.<sup>42</sup> Onel et al<sup>43</sup> reported on the successful use of video education in conjunction with physician encounters in preparing diagnosed prostate cancer patients for decision-making.

Chan and Sulmasy<sup>44</sup> have recently outlined the content that they believe to be appropriate for inclusion in an educational intervention aimed at facilitating informed decision-making about prostate cancer early detection. Prior to PSA testing, they recommend that, at a minimum, men should be advised that false-positive and false-negative results may occur and that it is not known whether PSA testing reduces prostate cancer mortality. They suggest that additional information about the pros and cons of prostate cancer early detection may be provided in the context of an encounter with a health care professional and via print materials.

#### FUTURE DIRECTIONS FOR RESEARCH

In the future, special attention should be devoted to examining the impact of preparatory education on informed decision-making about early detection in different high-risk population groups, including African American men and men with a family history of prostate cancer. The effects of preparatory education, as measured in terms of knowledge change, satisfaction with decision-

making, and behavior, should be assessed across the continuum of care. That is, in addition to preparing men to decide whether to undergo DRE and PSA testing, it is also important to facilitate decision-making about diagnostic evaluation and treatment. Recent reports suggesting that nonadherence to recommended follow-up treatment may be substantial among men with an abnormal early detection examination result<sup>45</sup> and that there may be significant racial differences in the use of aggressive therapy amplify the need for additional research in the area of preparatory education.<sup>46-48</sup>

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# Communicating Effectively With the Patient and Family About Treatment Options for Prostate Cancer

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To help the patient with prostate cancer, his family, and his friends, in coping with the diagnosis and its treatment, health care providers need to understand the controversies about treatment options and the impact that such controversies have on medical decision-making. To update health care providers, the authors reviewed all pertinent citations in the medicine database from 1966 to 2000, and in other relevant publications. These resources are also available to our patients through the Internet and other avenues, such as books and magazines. It is the role of the physician to counsel patients about their individual circumstances to allow them to make the best individualized treatment option. Patients who have appropriate information and are actively involved with the decision-making process are, in general, psychologically healthier. Though watchful waiting has no side effects, men must cope psychologically with issues of long-term cancer survivorship. With early detection, men can choose between different treatment options (eg, radiation versus radical prostatectomy). Urinary incontinence, sexual dysfunction, and fatigue are major emotional and physical stressors for this population. Providers of care need to be aware of the psychosocial sequelae of prostate cancer and treatment-related side effects and assist their patients in processing ever-growing data on the management of prostate cancer that technology brings. Copyright © 2000 by W.B. Saunders Company

**Key words:** Prostate cancer, psychosocial, depression, anxiety, quality of life.

While fear, anger, confusion, and depression are common reactions to all cancers, treatment for prostate cancer means dealing with impotence and incontinence. The biopsychosocial model<sup>1</sup> is discussed, as a guide for helping providers to deal with patients with prostate cancer and their families. This challenge is further amplified because information access on the part of the patient and family can often be overwhelming.

## Epidemiology

White men survive longer than African American, Hispanic, and American Indian men with prostate cancer, but survival rates for different races are simi-

lar when corrected for grade and stage.<sup>2</sup> African American men are twice as likely as white men to get prostate cancer and are more likely to be diagnosed at later stages. African American men who are 65 to 69 years old, with localized disease, are less likely to be treated with radical prostatectomy (RP).<sup>3,4</sup> RP is used more commonly in younger men (<60 years), and radiotherapy (RT) or watchful waiting is mostly used in older men (>70 years). Married men tend to be diagnosed earlier with prostate cancer. Lower socioeconomic groups are less willing than middle socioeconomic groups to participate in clinical trials because of their distrust of the medical community. Not surprisingly, survival rates are higher in married men from higher socioeconomic strata.<sup>5-7</sup>

## Biological Aspects

### Risk Factors

Possible risk factors for prostate cancer include African American race, increased age, family history of prostate cancer, a diet high in animal fat, and high plasma testosterone. Occupations associated with increased risk include printers, painters, rubber workers, textile workers, mechanics, loggers, ship fitters, farmers, and drug and chemical workers. Vasectomy and benign prostatic hyperplasia (BPH) do not appear to increase one's risk.<sup>8-10</sup>

Nutritional factors appear to play a role in the progression rate of prostate cancer. Vitamin D defi-

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ciency, polyunsaturated fats, and saturated fats may increase the risk of prostate cancer; monounsaturated fats may be protective. Selenium supplements and lycopene, an antioxidant found in tomatoes, may lower the risk of prostate cancer. Vitamin E may reduce the incidence of prostate cancer in men who smoke.<sup>11-13</sup>

In rare instances, prostate cancer is inherited by autosomal-dominant allele; 88% of carriers and 5% of noncarriers develop prostate cancer by age 85 years. Men with hereditary prostate cancer (HPC1) have a 90% risk of developing prostate cancer in their 90s. Male carriers of the breast cancer 1 (BRCA1) mutation are at three times greater risk than the general population. Receiving BRCA1 results impacts on quality of life, insurance, employment, and psychosocial well-being, but the health benefits of BRCA1 testing are unknown.<sup>14-16</sup>

In some studies, complementary and alternative therapies have been used to treat prostate cancer. Herbal therapies like PC-SPES\* have important biologic activities, such as decreasing the serum concentrations of testosterone and PSA; however, PC-SPES may interfere with conventional treatment. The benefit of herbs must be balanced against clinically significant adverse effects.<sup>17-20</sup>

### Clinical Diagnosis

Most patients with prostate cancer are asymptomatic at diagnosis; others report dysuria, urinary frequency, hematuria, dribbling, decreased force of the urinary stream, incomplete bladder emptying, and nocturia. Metastatic disease may present with pain in the back, hips, or perineal area; bowel or urethral obstruction; weight loss and fatigue.<sup>9</sup> There is no way to distinguish between slow-growing tumors and clinically significant tumors.<sup>21</sup> Treatment may not reduce disease-specific mortality for tumors discovered incidentally. Although 30% of men over 50 years old get prostate cancer, only 3% die of the disease. Aggressive treatment confers both morbidity and mortality.<sup>8</sup>

### Treatment

Treatment of prostate cancer depends on the patient's age, health, digital rectal examination, tumor

stage, PSA levels, prostate biopsies, Gleason scores, and response to prior treatments for prostate cancer.<sup>22</sup> Accepted therapies include watchful waiting, RP, RT, hormonal therapy, orchiectomy, and anti-neoplastic drug therapy. There is no consensus regarding the relative survival benefits of different treatment modalities. Patients can often obtain conflicting information from publications, web sites, and support groups. Faced with the diagnosis of a deadly disease, men simultaneously must confront threats to their sexuality and masculinity. Building rapport and trust during initial visits allows men to share their concerns. Survivors of prostate cancer must deal with treatment-related complications in the context of other age-related losses: health, energy, retirement, and deaths of peers and family members.

Patients with prostate cancer face several barriers to receiving appropriate psychiatric intervention. Cancers with sexual associations carry greater social stigma. North American men generally do not seek psychiatric help and tend to use mental health services less than women.<sup>23</sup> Whereas women feel better when they can express their feelings, men feel better when they can participate in the medical treatment decision-making process; they prefer not to overburden their families.<sup>24</sup> Older men may be less likely to agree to psychiatric evaluation or treatment and are unlikely to report emotional distress. Physicians tend to underestimate the psychological comorbidity of prostate cancer patients, and patients with subsyndromal psychiatric symptoms may remain untreated, even after identification. Roth and others described a paper thermometer scale to screen for psychological distress in prostate cancer patients, who might need psychiatric referral, detecting a high degree of distress (32.6% anxiety and 15.2% depression). However, 40% of the distressed men missed or refused their psychiatric interview. More than half of the men identified failed to meet the criteria for a psychiatric diagnosis.<sup>23,25</sup>

Although there is increasing emphasis for men to assume a more active role in treatment decision-making, not all men may be comfortable with this role. In 1997, Davison and Degner<sup>26</sup> studied whether improved information acquisition and assuming a more active role in treatment decision-making would lead to decreased anxiety and depression in men with newly diagnosed prostate cancer. Sixty newly diagnosed men with prostate cancer were randomly selected to receive either an intervention that consisted of a written information with discussion, list of questions to ask their physician, and an audiotape of the

\* PC-SPES is an estrogenic herbal combination consisting of eight herbs: saw palmetto, scutellaria (skullcap), *Ganoderma lucidum*, panax pseudo-ginseng, chrysanthemum, licorice, *Rabdosia rubescens*, and *isatis*.

medical consult, or a written information alone. At 6 weeks' post-intervention, lower state anxiety scores on the Spielberger State-Trait Anxiety Inventory were observed for the intervention group. The Center for Epidemiologic Studies Depression Scale (CES-D) did not reveal significant differences between the two groups.<sup>26</sup>

Localized prostate cancer may be managed by watchful waiting or may be treated with RP or RT. There are little published data on mortality in prospective, population-based studies for patients treated via RP or RT.<sup>27</sup> Watchful waiting may be most appropriate for older patients with low-grade tumors, who have other serious medical problems that make them poor surgical candidates. In an asymptomatic patient, whose life expectancy is less than 10 years, prostate cancer is unlikely to cause death. Disease progression is detected with periodic screening during watchful waiting, and treatment-related complications are avoided.<sup>28</sup> Patients may experience helplessness while not pursuing active treatment. They describe being "in limbo," waiting for their cancer to grow so that definitive treatment can begin.

RT may be used successfully for localized tumors and does not include a lymph-node dissection to determine the extent of disease (unlike RP). External beam irradiation requires visits, 5 days/week, for 8 weeks.<sup>29</sup> With transperineal placement of radioactive seeds under ultrasound guidance, the seeds are left in place and emit local radiation for a short period of time.<sup>9,27,30</sup>

RP involves complete surgical removal of the prostate, seminal vesicles, ampullae of the vas deferens, the vas deferens, and the bladder cuff. It includes lymph-node biopsies, and so the outcome from RP cannot be compared with RT.<sup>27,31</sup> Because prostate cancer progresses slowly, more than 10 years may be needed to fully compare the effectiveness of RP versus RT.<sup>27</sup>

Both RP and RT confer similar risks; mortality (0.2% to 0.3%), incontinence (0.8% to 0.9%), and impotence (30% to 70%) are the most common sequelae.<sup>30</sup> Urinary leakage maybe more common following RP than with RT. Reports of pad usage after RP vary in the literature with most men having minor or no urinary leakage by 6 months.<sup>32</sup>

Despite the newer "nerve-sparing" techniques, many men may become impotent immediately after surgery. Postoperative potency may be related to the number of spared neurovascular bundles, frequency of intercourse preoperatively, absence of seminal vesicle or lymph-node involvement with cancer, absence

of postoperative incontinence or stricture, age and cancer volume.<sup>32-34</sup> With RT, men may have a progressive loss over time in erectile function, suggesting that with time, post-treatment impotence may not differ significantly between men treated with RT versus RP.<sup>32</sup> Gastrointestinal problems are more likely to be seen after RT.<sup>29</sup> Specific authors may minimize or emphasize the clinical significance of different side effects secondary to RT versus RP. With patients reviewing the peer-reviewed literature on the Internet, their ability to critically evaluate the data presented may lead to false expectations with regards to outcome.

Although most impotence is treatment-related, for some men, psychogenic factors may be partly responsible and psychiatric intervention may be important.<sup>35</sup> In the past, as most elderly men had passed the traditional age associated with raising a family, less attention was paid to erectile function and the psychological consequence of impotence. However, older men are as likely to be disturbed by postsurgical impotence as younger men.<sup>36</sup> Etiology of erectile dysfunction after prostate cancer therapy is probably multifactorial. Arteriogenic impotence predominates among men undergoing RT. Venous-occlusive/cavernosal pathology predominates among men undergoing RP. Although most patients report problems in sexual/urinary function, global quality of life does not appear to be compromised following RP.<sup>37</sup>

Despite complaints of difficulty with erections, 60% of impotent patients did not use erectile aids (eg, injections, vacuum devices) for 12 months or longer after RP. Although impotency was a principal concern, most stated they would undergo surgery again for their peace of mind.<sup>36</sup> Sildenafil citrate (Viagra; Pfizer, New York, NY) can reduce erectile dysfunction. It is administered orally, once daily, and is less invasive compared with cavernosal injection and implantation of penile prostheses. According to the manufacturer, 43% of men who had erectile dysfunction following RP achieved adequate sexual function with sildenafil citrate.<sup>38</sup> Men have to be sexually aroused for the drug to be effective. Side effects of sildenafil citrate include headache, flushing, dyspepsia, and visual disturbances. The use of organic nitrates is absolutely contraindicated in patients taking sildenafil citrate. Sixty-nine deaths have been associated with sildenafil citrate: 46 had cardiovascular events, 21 unknown, and 3 had strokes.<sup>39</sup>

In advanced prostate cancer, therapy is aimed at disease control rather than cure. Asymptomatic patients may choose watchful waiting. Although

hormonal treatment (orchiectomy, estrogen use, or chemical castration) is preferred in symptomatic patients, it may not increase survival. Pain control should be assessed, as patients with pain suffer depression and anxiety.<sup>40</sup> Treatment, side effects, and quality-of-life concerns often influence patients' decision-making regarding treatment. Most individuals associate cancer with a slow, painful death.<sup>9,30,41</sup>

Physicians may underestimate the degree of emotional distress related to reduced libido, feeling unattractive, impotence, and incontinence. Men suffering from prostate cancer report impotence, fatigue, and incontinence as their primary concerns. Fatigue may be worsened by the increased demands of going for office visits, to the pharmacy, etc. Incontinence (ie, urine leakage, smelling of urine, and having to wear pads) leads to related demands to do more laundry and increased planning to participate in social activities. Following RP, some men may occasionally lose a few drops of urine when lifting heavy objects or coughing (ie, stress incontinence). Other men are left with very little control over their urine flow. Social isolation and embarrassment are understandable consequences.

## Psychological Aspects

### Anxiety

Between 25% and 47% of cancer patients suffer from psychiatric syndromes. Reactive anxiety is the most common reason for psychiatric referral of cancer patients.<sup>42</sup> The degree of anxiety and depression experienced by cancer patients (prostate included) was not measurably different between different cancer sites (ie, prostate, gynecologic, breast, lung, brain, colon, head and neck, hepatoma, and lymphoma) on the Brief Symptom Inventory.<sup>43</sup>

Post-traumatic stress disorder (PTSD)-related symptoms also have been reported in prostate cancer patients.<sup>44</sup> Patients may reexperience the traumatic events in dreams, disturbing recollections, and flashbacks.<sup>45</sup> Risk factors, such as poor social support, a history of traumatization/victimization, or previous psychiatric disorder, may predispose certain patients to PTSD. Cancer treatments are frequently intrusive and painful. Patients may feel a loss of control or experience helplessness in the face of life-threatening disease. In long-term cancer survivors, repeated treatments or recurrences may act as a series of stressors. Although 25% to 33% of all people, who experience traumatic events acquire PTSD, in one study, 4% of

female cancer survivors had PTSD.<sup>46</sup> Although no specific PTSD treatment has been proposed for cancer patients with PTSD, cognitive-behavioral therapies, support groups, and pharmacotherapy may be beneficial.

Kornblith et al<sup>44</sup> studied 173 men with prostate cancer and 83 spouses/partners, using the Intrusion Subscale of the Impact of Event Scale, and Selby's Quality of Life Uniscale. Both patients and spouses reported frequent intrusive thoughts and images. Spouses reported greater psychological distress than the patients. Prostate cancer patients exhibited no relationship between treatment severity or intensity, and intrusive or avoidant symptoms.<sup>44</sup> Drug companies believe that providing prostate cancer education to spouses, daughters, and partners help motivate men to seek medical attention for prostate problems.<sup>23</sup>

Clark et al<sup>47</sup> studied quality-of-life issues in men with metastatic prostate cancer and identified three key domains: self-perceptions, anxiety about the effects of treatment, and concerns about treatment decision-making. Many of the men reported anxious preoccupation or developing a fighting spirit in the face of their disease. Relationships with wives were altered. Though issues of intimacy and affection were troublesome for some men, impotence was emotionally distressing for most men. It was both difficult and comforting for spouses to emphasize emotional companionship. Body image, sexual problems, spouse affection, spouse worry, masculine image, cancer-related self-image, cancer distress, cancer acceptance, and regret over previously made decisions were areas of concern, particularly in men who had experienced many side effects.<sup>47</sup>

### Depression

Some sadness is not unusual when patients are diagnosed with prostate cancer. Physicians must distinguish between "normal" sadness in response to the cancer diagnosis and clinically significant depression.<sup>48,49</sup> Issues, such as cancer stage, clinical course, type of treatment, and presence of pain, must be considered in evaluating depression.<sup>50</sup> Although 20% to 25% of all patients with cancer may have a depressive disorder, depression often goes unrecognized. Neurovegetative symptoms may be due to the cancer or to the depression. Symptoms, which differentiate the depressive illness from cancer, include a sense of failure, social withdrawal, feelings of being punished, suicidal ideation, dissatisfaction, and indecision. Loss of interest and crying may present with more severe

depression. Risk factors for depressive disorders include social isolation, recent losses, a tendency to pessimism, socioeconomic pressures, previous mood disorder, alcohol or substance abuse, previous suicide attempt, poorly controlled pain, depressive side effects of medication, and metastatic cancer. Psychotherapy, psychopharmacology, psychoeducation, and electroconvulsive therapy are all effective treatments for cancer patients with depression. Antidepressants with significant anticholinergic side effects should be avoided in patients with urinary retention or reduced intestinal motility.<sup>48,49,51,52</sup>

### Social Aspects

Until recently, prostate cancer had not received the same attention as other cancers in the popular press. Despite increasing numbers of published personal accounts of prostate cancer, the stigma of having cancer and potentially impaired sexuality may prevent patients from seeking adequate social and psychological support. Furthermore, there may be confusion between BPH and prostate cancer, leading men to underestimate the seriousness of the disease.

Men with prostate cancer receive assistance with household matters, emotional support, and encouragement from their spouses. However, spouses (and partners) show greater psychological distress than their husbands do, and this increases as the patient's condition worsens. It is unclear if this reflects gender differences in reporting, or truly greater stress, induced by repeatedly witnessing intrusive, invasive, and painful treatments of a loved one while dealing with anticipatory bereavement.<sup>44</sup> One study suggested that wives preferred early detection strategies for their spouses that offer increased survival at the expense of quality of life. Decision-making strategies clearly vary among couples.<sup>7,53</sup>

Social support is positively correlated with psychological well-being, and low levels of social support correlate with increased mortality from all causes. Emotional support enhances self-esteem; informational support may provide advice or cognitive guidance. Social companionship provides contact with others and may provide a needed distraction from the stress of having cancer. Instrumental support can meet concrete needs by providing financial aid or material resources. Involvement in a social network can contribute to well-being by helping to develop feelings of predictability and stability. Social support buffering mechanisms for men are met through friendship, reassurance of worth, and reli-

able alliances. Companionship and task accomplishment adds to satisfaction. These social supports may translate into health benefits by positive influences on the functioning of neuroendocrine or immune systems, thereby acting as a buffer against disease. Other positive health-related effects include positive influences on behavior patterns (ie, smoking, alcohol use).<sup>7,51,53,54</sup>

Although it seems obvious that families caring for patients with prostate cancer are under emotional, physical, and financial strain, literature on prostate cancer caregivers is not available. Difficulties in communication and delays in care may result from inadequate knowledge or reluctance to ask about urologic needs or sexual symptoms. Dysfunctional and difficult families may find caregiving particularly overwhelming. Competent psychosocial intervention may help.<sup>26</sup> In a recent study, it was noted that cancer patients expressed a desire to have access to someone who might be able to spend more time with them. They also expressed the need for continuity of care.<sup>55</sup>

National support groups, such as "Us Too" and "Man to Man," can help meet the emotional and educational needs of prostate cancer patients. Interviews of some group members of "Us Too" and their primary care physicians revealed that although a high percentage of physicians recall discussing treatment options, side effects, and costs, a very low percentage of patients recall having had the same discussions. Notwithstanding, more than 90% of both physicians and patients believed that the patient's own primary physician was a good source of cancer-related information. Both patients and physicians believed that physicians are less likely to provide emotional support. Support groups can address unmet emotional and educational needs of prostate cancer patients and hopefully, minimize suffering.<sup>56-58</sup> Cunningham et al<sup>59</sup> have shown that coping skills training in small support groups improves mood and quality of life in a broad range of cancer patients.

Unfortunately, most survey instruments used to measure quality of life have not been standardized in this population, and complete data relating to quality of life is absent in the literature. Reliable questionnaires that are prostate-specific are being developed; however, physical function, pain, social activity, and sexual function are the most important areas of concern.<sup>60-62</sup> Most quality of life studies include physical functioning, activities of daily living, and patient-reported sense of well-being. There have been some reports of physician resistance to measuring quality of life. There is no consistency between which factors

were measured by different instruments. Quality of life researchers describe that problems in adaptation are seen most often in late-stage patients, who report greater pain, fatigue, and urinary difficulties.

Physicians often overestimate the level of physical functioning of a patient. Decreased sexual functioning, urinary incontinence, and bowel symptoms need to be considered in evaluating quality of life. Some men trade long-term survival for potency; others avoid decreased sexual potency at all costs. Personality, motivation, a strong support system of family and friends, favorable environmental factors such as living in a first floor apartment, having access to pharmacy, other stores, and appropriate medical care are important determinants of quality of life.<sup>44,63-66</sup> Patients, particularly poorer African American, may opt to forgo needed care in the absence of available and affordable means of transportation to treatment facilities. Health care providers need to work with patients, families, and volunteer agencies in the community to enhance transportation to cancer treatment.<sup>67</sup> Although racially and culturally sensitive educational outreach programs need to provide education about prostate cancer, the relationship between access to care and prostate cancer outcome remains unclear.<sup>68</sup>

Some indicators that are used to measure quality of life are body image, sexual problems, spousal affections, spousal worry, masculinity, cancer-related self-image, cancer distress, cancer acceptance, and regret of treatment decisions.<sup>69</sup> Self-perceptions, anxiety regarding treatment effects, and decision-making are equally important domains. Preservation of quality of life at the expense of survival requires a clear understanding of what this trade-off entails.<sup>70</sup> Quality-adjusted survival rates may not be appropriate to use in determination of treatment plans due to variations in individual values. It may be unreasonable to base treatment expectations on a return to the patient's premorbid level of functioning.

Because there is no therapy that is clearly superior for all patients and because all treatments carry risks of side effects, quality of life considerations become increasingly important in decision-making models. Often, patients are faced with complex decisions, which need to be made within a moderate time frame and for which they were ill-prepared. Recent studies have attempted to incorporate educational programs into standard office visits. Determination of patient treatment preferences, using various decision-making aids, may facilitate decisions regarding early de-

tection and treatment.<sup>71</sup> Development of treatment programs is hindered by lack of consensus regarding optimal treatment for prostate cancer. One study of 21 large managed care organizations indicated that no treatment policy was in place for any of the managed care companies surveyed.<sup>72</sup>

## Conclusions

Men who are diagnosed with prostate cancer experience uncertainty related to the time course of the cancer and often fear treatment and treatment-related side effects. Health care providers need to consider patient and family beliefs in the context of ethnocentric values. Although most patients are able to adapt to the cancer diagnosis and its management, quality of life and treatment complications should be discussed by physicians who counsel patients in the selection of preferred courses of treatments. Treatment choices are made more difficult by the lack of information on the long-term relative effectiveness of RP versus RT. Health care providers should be aware of the resources (eg, books, Web sites, support groups) that a given patient may be using to guide their decision-making process.

Ideally, the management of anxiety and depression requires a multidisciplinary and multimodal approach. Psychiatrists can assist as diagnostic consultants, in monitoring adjuvant psychotropic medications, and in providing appropriate psychotherapy for treatment for men with prostate cancer and their families. An understanding of the current controversies in early detection and treatment can assist the health care provider in working through difficult medical decisions with patients with prostate cancer and their families.

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# Chart Audit Form

<b>Patient Name</b> _____	<b>Auditor</b> _____
<b>Address</b> _____	<b>Audit Date</b> ____/____/____
<b>Tel. No.</b> _____	<b>Practice</b> _____
<b>Patient Birthdate</b> ____/____/____	
<b>Patient Number</b> _____	

## Section A. Prostate Disease History

### A-1 Prostate Cancer, Personal History

- ☐ Yes ➡ ➡ ➡  
☐ No  
☐ Unknown

Date of diagnosis \_\_\_\_/\_\_\_\_/\_\_\_\_  
Stage at diagnosis \_\_\_\_\_  
Gleason score \_\_\_\_\_

### A-2 BPH, Personal History

- ☐ Yes ➡ ➡ ➡  
☐ No  
☐ Unknown

Date of diagnosis \_\_\_\_/\_\_\_\_/\_\_\_\_

### A-3 Prostatitis, Personal History

- ☐ Yes ➡ ➡ ➡  
☐ No  
☐ Unknown

Date of diagnosis \_\_\_\_/\_\_\_\_/\_\_\_\_

### A-4 Prostate Cancer, Family History

- ☐ Yes ➡ ➡ ➡  
☐ No  
☐ Unknown

#### Check all that apply

- ☐ Father  
☐ Brother(s) ➡ ➡ Number of brothers \_\_\_\_  
☐ Grandfather, maternal  
☐ Grandfather, paternal  
☐ Grandfather, unknown lineage  
☐ Uncle(s), maternal ➡ ➡ No. of uncles \_\_\_\_  
☐ Uncle(s), paternal ➡ ➡ No. of uncles \_\_\_\_  
☐ Uncle(s), unknown lineage ➡ ➡ No. of uncles \_\_\_\_

## Section B. Prostate Screening History

### B-1. DRE

☐ Yes ➡ ➡ Number of DRE's \_\_\_\_\_ recorded in chart

☐ No

Most recent DRE

DRE date / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

DRE result ☐ Normal

☐ Abnormal (specify) \_\_\_\_\_

DRE reason ☐ Screening

☐ Symptoms

☐ Unknown

☐ Other (specify) \_\_\_\_\_

### B-2. PSA

☐ Yes ➡ ➡ Number of PSA's \_\_\_\_\_ recorded in chart

☐ No

Most recent PSA

PSA date / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

PSA result \_\_\_\_\_ ng/ mg

PSA reason ☐ Screening

☐ Symptoms

☐ Unknown

☐ Other (specify) \_\_\_\_\_

### B-3. Urology Referral

☐ Yes ➡ ➡ Number of referral's \_\_\_\_\_ recorded in chart

☐ No

Most recent referral

Referral date / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

Referral reason ☐ Abnormal DRE

☐ Abnormal PSA

☐ Unknown

☐ Other (specify) \_\_\_\_\_

Urologist name \_\_\_\_\_

Report in chart ☐ Yes ☐ No

**B-4. TRUS**

☐ Yes ➡ ➡ Number of TRUS's \_\_\_\_\_ recorded in chart

☐ No

**Most recent TRUS**

TRUS date / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

TRUS result ☐ Normal

☐ Abnormal (specify) \_\_\_\_\_

TRUS reason ☐ Follow-up Abnormal DRE

☐ Follow-up Abnormal PSA

☐ Unknown

☐ Other (specify) \_\_\_\_\_

Urologist name \_\_\_\_\_

Report in chart ☐ Yes ☐ No

**B-5. Biopsy**

☐ Yes ➡ ➡ Number of biopsies \_\_\_\_\_ recorded in chart

☐ No

**Most recent biopsy**

Biopsy date / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

Biopsy result ☐ Normal

Biopsy reason ☐ Abnormal (specify) \_\_\_\_\_

☐ Follow-up Abnormal DRE

☐ Follow-up Abnormal PSA

☐ Unknown

☐ Other (specify) \_\_\_\_\_

Urologist Name \_\_\_\_\_

Report in chart ☐ Yes ☐ No

## Section C. Comorbidities by System

### C-1 Cardiovascular

#### A... Past Myocardial Infarction

- ☐ Yes    ➡    ➡  
☐ No

Date of most recent event / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

#### B... Congestive Heart Failure

- ☐ Yes    ➡    ➡  
☐ No

Date of most recent acute CHD episode or a CHF-related hospitalization / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

#### C... Peripheral Vascular Disease

- ☐ Yes    ➡    ➡  
☐ No

☐ Intermittent Claudication

☐ Other \_\_\_\_\_

#### D... Atherosclerorosis

- ☐ Yes  
☐ No

#### E... Other

- ☐ Yes    ➡    ➡  
☐ No

(specify) \_\_\_\_\_

### C-2 Respiratory

#### A... Dyspnea

- ☐ Yes    ➡    ➡  
☐ N

Date of most recent episode / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

#### B... Asthma

- ☐ Yes    ➡    ➡  
☐ No

Date of most recent severe episode / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

#### C... COPD

- ☐ Yes  
☐ No

*NOTE: Include chronic bronchitis and chronic emphysema*

#### D... Other respiratory condition

- ☐ Yes    ➡    ➡  
☐ No

Specify \_\_\_\_\_

### C-3 Cerebral

#### A... Stroke

- ☐ Yes    ➡    ➡  
☐ No

Date of most recent stroke / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

Any indication of residual impairments (e.g., paralysis)?

☐ Yes    ☐ No

**B... Transient Ischemic Attack(s)**

☐ Yes    ➡    ➡  
☐ No

Date of most recent TIA / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

**C... Dementia**

☐ Yes    ➡    ➡  
☐ No

☐ Alzheimer's Disease

☐ Other \_\_\_\_\_

**D... Other Cerebral condition**

☐ Yes    ➡    ➡  
☐ No

Specify \_\_\_\_\_

---

**C-4 Endocrine**

**A... Diabetes**

☐ Yes    ➡    ➡  
☐ No

Date of diagnosis / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

Any indication of diabetes-associated retinopathy, neuropathy, or nephropathy?

☐ Yes    ☐ No

Any indication of any past diabetes-associated hospitalizations?

☐ Yes    ☐ No

**B... Other endocrine condition**

☐ Yes    ➡    ➡  
☐ No

Specify \_\_\_\_\_

---

**C-5 Renal**

**A... Chronic Renal Failure**

*Include renal insufficiency, uremia, dialysis dependency, past renal transplant or removal of one kidney or non-functioning kidney.*

☐ Yes    ➡    ➡  
☐ No

Any indication of dialysis dependency or past renal transplantation?

☐ Yes    ☐ No

**B... Other renal condition**

☐ Yes    ➡    ➡  
☐ No

Specify \_\_\_\_\_

---

**C-6 Hepatic**

**A... Cirrhosis**

☐ Yes    ➡    ➡  
☐ No

Any indication of portal hypertension?

☐ Yes    ☐ No

**B... Chronic Hepatitis**

☐ Yes    ➡    ➡  
☐ No

Specify type \_\_\_\_\_

**C... Esophageal Varices**

☐ Yes  
☐ No

---

**D... Other hepatic condition**

☐ Yes    ➡    ➡  
☐ No

Specify \_\_\_\_\_

---

**C-7    Gastrointestinal**

**A... Peptic Ulcer**

☐ Yes    ➡    ➡  
☐ No

Any indication of bleeding that required transfusion?

☐ Yes    ☐ No

**B... Other GI condition**

☐ Yes    ➡    ➡  
☐ No

Specify \_\_\_\_\_

---

**C-8    Neoplastic**

**A... Solid Tumor(s)**

☐ Yes    ➡    ➡  
☐ No

Date of initial treatment / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

Specify solid tumor \_\_\_\_\_

Any indication that this tumor is metastatic?

☐ Yes    ☐ No

**B... Lymphoma or Leukemia**

☐ Yes    ➡    ➡  
☐ No

Date of initial treatment / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

**C... Malignant Melanoma**

☐ Yes    ➡    ➡  
☐ No

Date of initial treatment / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

**D... Other neoplastic condition**

☐ Yes    ➡    ➡  
☐ No

Date of initial treatment / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ /

Specify \_\_\_\_\_

---

**C-9    HIV and AIDS**

**A... HIV seropositive**

☐ Yes    ➡    ➡  
☐ No

Did initial treatment occur within 5 years of this audit?

☐ Yes    ☐ No

**B... AIDS diagnosis**

☐ Yes    ➡    ➡  
☐ No

Did initial treatment occur within 5 years of this audit?

☐ Yes    ☐ No

---

**C-10    Sexually transmitted disease**

**Sexually transmitted disease**

☐ Yes    ➡    ➡  
☐ No

Specify \_\_\_\_\_

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# **A Follow-up Survey**

## **What You Think about Prostate Cancer Screening**

<< *Practice Name*>>

and

**Thomas Jefferson University**

To \_\_\_\_\_

### **About the Survey**

This survey is a follow-up to the one that you completed about six months ago. We want to learn what you think *now* about being checked for prostate cancer with a rectal exam and prostate specific antigen (PSA) test. The survey will take about 10 to 15 minutes to complete. Your name will not be used in any reports about this survey.

### **How to Complete the Survey**

For all of the items in this survey, please check only *one* response box for each item. If you are not sure, please check the response that is closest to your ideas.

### **How to Return the Survey**

Please return the survey in the envelope that comes with the survey. The envelope is addressed to Dr. Ronald E. Myers at Thomas Jefferson University. It already has postage. You can just drop it into a mailbox.

**Thomas Jefferson University**

**Institutional Review Board**

Approval Date 4-12-01

Annual Review Due 5-26-01

Consent Form Not Valid After 7-26-01

## Part A. Ideas About Prostate Cancer

For each item, please check True or False.

- A-1. Experts agree that men should be checked for prostate cancer. ☐ True ☐ False
- A-2. Doctors can tell if a prostate cancer is slow growing (not dangerous) or fast growing (dangerous). ☐ True ☐ False
- A-3. Being treated for cancer can cause men to have problems holding their urine (incontinence). ☐ True ☐ False
- A-4. There is clear proof that being treated for prostate cancer saves lives. ☐ True ☐ False
- A-5. Being treated for prostate cancer can cause men to have problems holding an erection (impotence). ☐ True ☐ False

For each item, please check Agree or Disagree.

- A-6. I think the benefits of prostate cancer screening outweigh any difficulty I might have in going through the tests. ☐ Agree ☐ Disagree
- A-7. Men who go through prostate screening will have more problems than men who do *not* go through the tests. ☐ Agree ☐ Disagree
- A-8. I think African American men are more likely to develop prostate cancer than white men. ☐ Agree ☐ Disagree
- A-9. I believe that when prostate cancer is found early, it can be cured. ☐ Agree ☐ Disagree
- A-10. I think that men who have a father or brother with prostate cancer are more likely to develop prostate cancer than men who do *not* have a father or brother with prostate cancer. ☐ Agree ☐ Disagree



## Part B. Decision About Being Checked for Prostate Cancer

For each item, please check one response.

**B-1.** Did you discuss being checked for prostate cancer with a doctor?

☐ No

☐ Yes

What did the doctor recommend?

☐ Be checked for prostate cancer

☐ Do **not** get checked for prostate cancer

☐ The doctor made **no** recommendation

**B-2.** What have you decided about being checked for prostate cancer in the future?

☐ I want to be checked for prostate cancer.

☐ I do **not** want to be checked for prostate cancer.

☐ I have **not** decided about being checked for prostate cancer.

Go to Part C, page 5

## Part B. Continued

If you have decided about being checked for prostate cancer in the future,  
please check Agree or Disagree for each item.

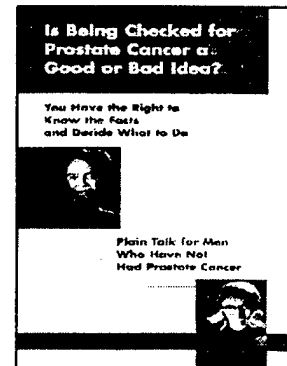
- B-3. This decision was easy for me to make. .... ☐ Agree ☐ Disagree
- B-4. I'm sure what to do in this decision. .... ☐ Agree ☐ Disagree
- B-5. It's clear what choice is best for me. .... ☐ Agree ☐ Disagree
- B-6. I'm aware of my options in this decision. .... ☐ Agree ☐ Disagree
- B-7. I feel I know the *advantages* for each option. .... ☐ Agree ☐ Disagree
- B-8. I feel I know the *disadvantages* of each option. .... ☐ Agree ☐ Disagree
- B-9. I feel I have made an informed choice. .... ☐ Agree ☐ Disagree
- B-10. My decision shows what is important to me. .... ☐ Agree ☐ Disagree
- B-11. I expect to stick with my decision. .... ☐ Agree ☐ Disagree
- B-12. I am satisfied with my decision. .... ☐ Agree ☐ Disagree

## Part C. Booklet

About six months ago, we sent you a booklet about prostate cancer and early detection, called

***Is Being Checked for  
Prostate Cancer a  
Good or Bad Idea?***

The next group of questions are about that booklet.



C-1. Do you remember receiving a copy of this booklet shown above?

☐ Yes

☐ No → Go to Part D

C-2. Did you read the booklet?

☐ Yes

☐ No → Go to Part D

C-3. Did the information in the booklet help you to make a decision about being checked (or not being checked) for prostate cancer?

☐ Yes

☐ No

C-4. Would you recommend the booklet to other men?

☐ Yes

☐ No

☐ Don't Know

## **Part D. Talk With Health Educator**

About six months ago, a health educator from our office contacted you to discuss prostate cancer early detection.

The next group of questions are about talking with the health educator.

**D-1.** Do you remember talking with the health educator?

☐ Yes

☐ No → **Go to Part E below.**

**D-2.** Did the information you talked about help you make a decision about being checked for prostate cancer?

☐ Yes

☐ No

**D-3.** Would you recommend talking with the health educator to other men?

☐ Yes

☐ No

☐ Don't Know

## **Part E. Returning the Survey**

**Please return the survey in the envelope provided with the survey.  
The envelope already has postage. You can just drop it into a mailbox.**

Ronald E. Myers, PhD  
Thomas Jefferson University  
Sheridan Building, Suite 403  
125 South 9<sup>th</sup> Street  
Philadelphia, PA 19107

**Thank you.**

## Community Practices and JIMA Endpoint Survey Follow-up Call to Non-responders

Instructions	Script
Introduction	Mr. <patient_last_name>, this is <caller_name>. I'm calling for Dr. <doctor_name>office.
Explain reason for call	<p>This office is working with Dr. Ronald Myers at Thomas Jefferson University on a research project. About &lt;&lt;six&gt;&gt; months ago, you completed a survey about prostate cancer screening.</p> <p>Then about &lt;&lt;two&gt;&gt; weeks ago, we sent you a follow-up survey.</p>
Determine status of survey	<p>I'm calling because we haven't gotten a follow-up survey back from you.</p> <p>Did you get the survey in the mail?</p>
IF NO	I can mail another copy to you. Let me check to make sure that we have the correct address. The address we have for you is . . .
IF YES	Have you had a chance to look it over?
Determine if any questions	Do you have any questions about the survey?
IF NO	GO TO Give reinforcement
IF YES	Respond <u>or</u> Offer to have Dr. Myers call.
Give reinforcement	
Confidentiality	All of your answers are confidential. They will only be used by the people working on this project. Your name will not be used in any reports about this research project.
Incentive	<p>When you complete and return the survey, we will send you \$20.</p> <p>We want to express our thanks to you for <u>taking the time to share your thoughts with us.</u></p>
Timeliness	It would be most helpful to us if you could return the survey in the next day or so.
Closing	Thanks for taking time to talk with me. We'll be looking forward to receiving your survey.

## Informed Choice among African American Men in the Negative Biopsy Trial

### A. SPECIFIC AIMS

Achieving adequate racial/ethnic group representation in cancer clinical trials is necessary in order to assess efficacy in diverse populations. It has been reported that participation among African American men in cancer prevention and treatment trials is low. This situation has the effect of limiting the extent to which findings from clinical trials can be generalized to this high-risk population group. Unfortunately, little is known about factors that serve to limit participation in this group; and, literature on effective methods for encouraging African American men to consider participation is scant. We need to address these gaps in knowledge in order to learn how to increase access to clinical trial opportunities for this population group. This need is especially acute in relation to the involvement of African American men in prostate cancer prevention trials.

The lifetime risk of developing prostate cancer and of dying from the disease rises substantially among men after the age of 50 (1), and a two-fold greater risk exists among African American men (2-4). In response to this epidemic, prostate cancer prevention trials have been developed and are being implemented to address the national problem (5). The "*Phase III Trial of Selenium for Prostate Cancer Prevention*" (CA-77789), or *Negative Biopsy Trial* (NBT), is a prevention trial that is designed to test the impact of selenium (Se) on prostate cancer risk. In this trial, white and nonwhite men who have had a negative prostate biopsy are randomized to one of three groups: a placebo control group, a group receiving 200 micrograms of Se daily, or a group receiving 400 micrograms of Se daily. Thomas Jefferson University Hospital (TJUH) is an NBT study site. We propose to conduct a pilot study related to the recruitment of African American men to the NBT. Specific aims of our proposed study are to:

1. Develop an educational intervention to facilitate decision making about enrollment in prostate cancer prevention trials in general (and in the NBT in particular).
2. Pre-test the feasibility and appropriateness of the intervention.
3. Pilot-test the intervention to obtain a preliminary assessment of its impact (in terms of attitudes, knowledge, and intention regarding trial enrollment).

More definitively, we will develop an educational counseling intervention (i.e., a participant education booklet and a nurse-led educational counseling session) designed to promote informed decision-making about trial enrollment. We will also develop a survey instrument to measure subjects' background characteristics, knowledge, attitudes, intention, and decision making about trial enrollment. Finally, we will pilot-test the intervention in a sample (N = 25) of African American men in order to assess the feasibility of data collection and intervention delivery and to obtain a preliminary assessment of intervention impact.

The parent grant for this application is *Increasing Access to Clinical and Educational Studies* or the ACES project (U01 CA86084). The ACES project is intended to: organize a cancer education awareness and research network among African American and other special populations in the Philadelphia area; recruit minority scientists (referred to here as special populations investigators) who have the potential to become co-investigators on pilot studies and develop investigator-initiated grant applications; implement cancer awareness education for health care providers who serve special populations; design and implement pilot studies involving project special populations investigators; and, submit new research grant applications that are designed to increase the participation of African Americans in cancer prevention and control research. Ronald E. Myers, Ph.D. is the Research Director of the ACES project and will serve as Principal Investigator for the pilot study. Kathleen Jennings-Dozier, Ph.D., M.P.H., R.N., C.S., an Associate Professor in the College of Nursing and Health Professions, MCP Hahnemann University, Philadelphia, PA and an African American, will be the Co-Leader of the study. Dr. Jennings-Dozier has been approved by the ACES project Steering Committee as a Special Populations Investigator. She participates in the ACES project Prostate Cancer Clinical/Educational Studies Workgroup. The steering committee has also reviewed and approved the proposed pilot study. Preliminary data collected in this investigation will be used to develop a new research grant application.